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Exploring the changing multidimensional
experiences of frail older people towards the
end of life: a narrative study.

ANNA E LLOYD



Thesis presented for the Doctor of Philosophy

The University of Edinburgh

2015

DECLARATION

I hereby declare that

- i. This thesis has been composed by myself.
- ii. The work presented within this thesis is my own unless otherwise stated.
- iii. This work has not been submitted for any other degree or professional qualification.

Anna E Lloyd

March 2015

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Preface

In the Beginning

This thesis is the culmination of an extended period of research carried out on a part time basis. I came to the study having trained as a nurse then completed a BSc in Psychology followed by an MSc in Health Psychology. I had worked within general hospitals, within nursing homes and as an assistant psychologist in a memory clinic for older people suffering from dementia. I wanted to find a way to combine my academic training with my professional experience of working with older people and to do something useful. I was then extremely fortunate to find that the primary palliative care research team at Edinburgh University were hoping to proceed with research to investigate the end-of-life needs and experiences of frail older people. Funding was then awarded by the Economic and Social Research Council. This PhD offered a unique opportunity to combine my background in nursing and psychology and interest in the lives of older people. The thesis is the outcome of the subsequent research.

Overview of the thesis

In chapter one I introduce the background to the study by describing the way that people die in the UK and the extent of palliative care need in older people with frailty and dementia. I follow by outlining the conceptual understandings and models of frailty and offer the definition and criteria used for the purpose of the study. I then describe end-of-life trajectories according to different illness groups and how multidimensional needs have been described for those with cancer and organ failure and how these differ.

Chapter two presents a narrative literature review of longitudinal studies of frail older people towards the end of life and incorporates cross sectional literature to illustrate differing dimensions of need. I then bring in the contributions of longitudinal research looking at older people generally and illustrate the need for contextualised qualitative longitudinal research to help understand the multidimensional needs of frail older people towards the end of life.

Chapter three describes the theoretical framework which underpins the interpretations and analysis and explains the design of the study. I describe how recruitment took place and how the data were generated and then analysed and consider the reflexivity inherent in the process of the research.

Chapter four provides a description of the pragmatics of how the study was conducted including details of the participants and specifics of the interviews.

In chapters five, six and seven I tell the individual case stories of the participants. The stories are grouped according to their relationship to how the older person managed the maintenance or loss of their sense of self. These are presented chronologically and attempt to show how the lives of the older people changed over time by incorporating the accounts of the older people, their informal carers and involved professionals. Each story ends with a summary and each chapter concludes by bringing the stories together and offering interpretation of the narrative form at a personal and societal level.

Chapter eight highlights the losses and sustaining capacities in the different dimensions of need that challenge or enable the older people to maintain a sense of self and cohesive narrative. I bring together the changing experiences of the frail older people in the different narratives as potential multidimensional trajectories and suggest an overarching trajectory of the narrative of frailty towards the end of life. I then incorporate theories of biography and identity and consider the source of fears that the frail older people voiced. I continue by considering the benefits and constraints of using a longitudinal, multi-perspective design.

In chapter nine I situate the findings in a discussion of the possible implications for practice and research. I reflect on ways that frail older people could be enabled to maintain their sense of self and a cohesive narrative and how a palliative approach to care could be considered.

Abstract

Background

Palliative care services have widened beyond cancer in recent years, yet frail older adults rarely receive such services. There is a need to understand the dynamic multidimensional end-of-life experiences of this group in order to assess how or if a palliative approach could be beneficial. Physical end-of-life trajectories for frail older people have been described but there remains little person centred research that describes changing experiences across physical, social, psychological and existential dimensions.

Aims and objectives

To explore the changing multidimensional experiences of frail older people towards the end of life and to reflect on the utility of a qualitative longitudinal multi-perspective design for this population.

Methods

Thirteen cognitively intact, community dwelling older adults considered to be moderately or severely frail, using a clinical frailty scale, and thirteen nominated informal carers participated in up to three narrative interviews over eighteen months. Eight nominated professionals were also interviewed. The interviews were participant led, audio-recorded and fully transcribed. The ‘voice centred relational’ narrative method, incorporating analyses of multidimensional experience, was used to analyse the data. The data were then analysed longitudinally to compile case studies for each older person.

Findings

The narratives of these frail older people approaching the end of life illustrate patterns of multidimensional experience that differ from the end-of-life trajectories of other groups. All participants experienced physical decline however three possible patterns of psychological, social and existential experience emerged. These

were stable, regressive and tragic according to the capacity to hold on to core values, and maintain a sense of self and of belonging in the world and are illustrated using visual trajectories. When the sense of self was threatened these frail older people lacked valued alternative identities and struggled with the absence of clear causative factors to explain their circumstances. The participants frequently described fears of burdening others, of moving to a nursing home or of developing dementia more than fears of dying. Losses and sustaining factors are described for physical, social, psychological and existential dimensions revealing the importance of social and community networks for supporting frail older people. There were constraints and benefits to using a qualitative longitudinal multi-perspective method, however the method enabled a deep, contextualised and rich understanding of the dynamic experiences of frail older people.

Conclusion

Frail older people may be supported towards the end of life by considering ways to promote the integration of the self. This may involve promoting valued alternative identities, protecting personhood through social and health care practices and by investigating ways to alleviate or make tolerable greatest fears. Community health and social care structures and social and community networks appear essential for addressing the end-of-life needs of frail older people. A qualitative, longitudinal, multiperspective design was beneficial for investigating the experiences of frail older people.

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A Note About Language

Throughout the thesis there are some terms used that I wish to clarify.

The first concerns the use of ‘palliative care’ and ‘end-of-life care’. These terms can become confused and conflated and can be described differently in different areas and by different bodies. For the purposes of the thesis the terms will relate to the differentiation described in: *More Care Less Pathway: Review of the Liverpool Care Pathway*. J Neuberger, C Guthrie, D Aaronovitch - Department of Health, Crown Copyright, 2013

End-of-Life: patients are classed as reaching the end-of-life when they are likely to die within the next 12 months.

Palliative Care: focuses on the relief of pain and other symptoms and problems experienced in serious illness. The goal of palliative care is to improve quality of life, by increasing comfort, promoting dignity and providing a support system to the person who is ill and those close to them.

Using the above definitions I thus describe the use of the terms ‘end-of-life care’ and ‘approaching the end of life’ within the thesis as follows:

End-of-Life care: I define end-of-life care as that which applies when an individual is thought likely to die within the next 12 months.

Approaching/towards/nearing the end of life: There is a great deal of difficulty in anticipating when death may occur for frail older people who may remain frail for many months or years. Accordingly I deliberately use the terms ‘approaching, towards or nearing the end of life’. Doing so refers to the period of time where older people may or may not be considered to be actively dying but have needs for support and symptom relief. This period of life may last for weeks, months or years for frail older people.

Abbreviations

ADL – Activities of Daily Living

BMI – Body Mass Index

COPD – Chronic Obstructive Pulmonary Disease

DNACPR – Do not attempt cardiopulmonary resuscitation

ESRC – Economic and Social Research Council

GDS – Geriatric Depression Scale

GP – General Practitioner

GSF – Gold Standards Framework

IADL – Independent activities of daily living

MDS-HC – Minimum Data Set for Home Care

MMSE – Mini Mental State Exam

NHS – National Health Service

OT – Occupational Therapist

PACE – Programme for All-Inclusive Care

QLR – Qualitative Research

QLLR – Qualitative Longitudinal Research

QT – Quantitative

REC – Research Ethics Committee

SES – Socio economic Status

SNHCP – Silver Network Home Care Programme

UK – United Kingdom

VCRM – Voice Centred Relational Method

WHO – World Health Organisation

Chapter 1: Introduction

I've seen sae many changefu' years,
On earth I am a stranger grown;
I wander in the ways of men,
Alike unknowing, and unknown:
Unheard, unpitied, unreliev'd,
I bear alane my lade o' care,
For silent, low, on beds of dust,
Lie a' that would my sorrows share.

I am a bending aged tree,
That long has stood the wind and rain;
But now has come a cruel blast,
And my last hald of earth is gane.

Lament for James, Earl of Glencairn: Robert Burns

1.1 Introduction

“Life – and I don’t suppose I’m the first to make this comparison - is a disease: sexually transmitted, and invariably fatal” (Gaiman, McKean, & Berger, 1994). Death is certain but the manner in which death will happen is not. Our ways of living have changed unrecognisably over recent decades and so have our ways of dying. We have seen life expectancies improve along with the eradication of communicable diseases that were major causes of death in previous centuries. Thus reaching the end of life generally follows a diagnosis of cancer, chronic illness with organ failure or frailty and dementia.

Some years ago I attended a lecture on the broad remit of caring for those at the end of life. At this lecture the presenter asked the audience to choose what they would like to die from. With little thought most people opted for a sudden death yet were told that this could not be chosen as it is now so very unlikely. The audience visibly and audibly struggled with the dilemma and I noticed that most then settled on a death from cancer. This surprised me, given that the audience was largely made up of health care professionals who must surely be only too aware of the potential for pain and distress in a cancer death. There are a number of possible reasons for this,

including the element of predictability of the trajectory, the shorter timescale and potentially less debilitating nature of cancer. However, more importantly it may be because cancer is the best managed in terms of end-of-life care. Their decision, then, may not just be understandable but revealing.

1.2 Current Provision of Palliative Care Services

Current palliative care services remain predominantly for those with cancer (Audit Scotland, 2008). This may be because of historical reasons and the predictable nature of the end-of-life trajectory for individuals dying with cancer; however, the majority of deaths occur following either organ failure or frailty and dementia. As figure 1 shows, more people die following a period of decline in frailty or dementia than cancer or organ failure.

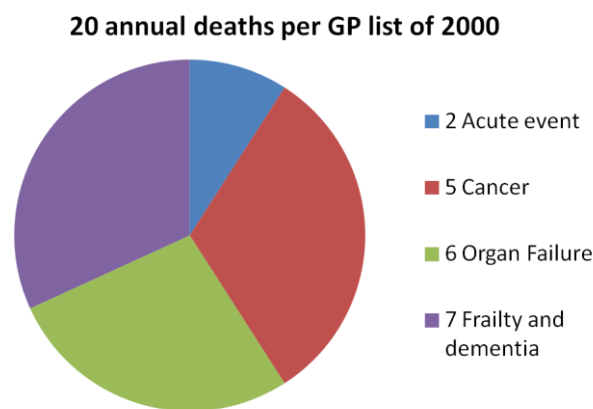


Figure 1: Deaths by cause in a typical UK General Practice

Reproduced with thanks from the GSF (Thomas.K, 2011)

When considering the extent, or the prolonged burden, of actual end-of-life need the impact of frailty and dementia increases further. Based on the death frequencies of

figure 1, figure 2 reveals that because of the longer time period of need towards the end of life of those who die following frailty or dementia, (estimated at six to nine months for cancer, 12 to 24 months for organ failure and two to four years in frailty and dementia) the volume or need for services in the community relates mostly to the frailty and organ failure trajectories. Indeed on this basis, at any point in time, around two thirds of people in primary care who would benefit from support in their last phase of life will be in this cohort of people with frailty or dementia. Yet they are currently underserved, with less than 20% being identified for supportive or palliative care before they die, and only in their last weeks of life (Zheng et al., 2013).

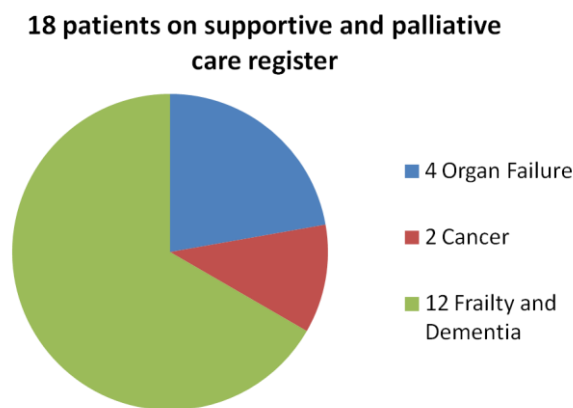


Figure 2: The illness profiles, per 2000 patients in primary care who are in their last phase of life, and may have supportive and palliative care needs.

Similarly, within the acute hospital setting a third of patients have been identified as having palliative care needs, with the majority of those being admitted primarily because of frailty (Gardiner et al., 2012). The need for palliative care for frail older adults has also been stated by The World Health Organisation (WHO), concluding that because of inadequate care planning and lack of access to appropriate services,

frail older persons suffer unnecessarily towards the end of life (Davies & Higginson, 2004). Their needs may relate to multiple co-morbidities and attendant treatment complications which lead to cumulative effects of overall greater impairments. These may be exacerbated by the hardships of social isolation, economic difficulties and poor physical or mental function.

The WHO has called for a palliative care approach to be adopted in the care of older people, defining palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. A model of palliative care based on the established cancer care services is unlikely to be effective for frail older people because, while many similar symptoms such as pain, fatigue and distress may be present, at a very simplistic level the physical trajectory of dying is more gradual and less uniform.

The Scottish government has committed to delivering palliative care on the basis of clinical need rather than diagnosis (Scottish Executive, 2007) while the English End-of-Life Care Strategy has outlined the necessity to develop services tailored to the needs expressed by patients and their carers, including frail older people within this remit (The Gold Standards Framework, 2007). Support can be found for this claim in a study looking at the experiences of frail older adults in relation to emergency hospital admissions and use of services (Themessl-Huber, Hubbard, & Munro, 2007). Older people claimed that the services offered to them did not meet their needs, or that they were in fact too frail to make use of them, and that they lacked flexibility. Accordingly, further investigation of the care needs for frail older people from their own perspective and the perspectives of those close to them is required.

1.2.1 Needs of Frail Older People towards the End of Life

There is a broad literature base regarding older people, hailing from disciplines such as medicine, nursing, social work, social care and policy, sociology, psychology, and

within specialities such as gerontology, geriatrics and psychiatry. However, little research has specifically investigated the needs or experiences of individuals approaching the end of their lives on the basis of being considered frail. Although two-thirds of frail older adults have multiple medical conditions, 32% have been shown to have none or only one of nine common long term illnesses with adverse outcomes remaining independent of their presence (Fried et al., 2001). Thus focusing on diagnostic categories may not be helpful for understanding the needs of a heterogeneous frail older population. Also attempting to translate research evidence on those with a specific clinical condition is potentially unhelpful when comorbid illnesses may also be present towards the end of life.

In a similar vein, focusing on care homes misses community dwelling frail older people. Given that 400,000 of the 10 million adults over the age of 65 in the UK live in residential care or nursing homes (Walshe, 2011) a substantial number of older adults remain in the community. Although increasing frailty increases the likelihood of an older person residing in a care home, there remains approximately half a million people over the age of 75 receiving social services at home and 2.5 million with informal home care from close relatives, friends and neighbours (The Information Centre: cited in Cornwell, 2012).

A further difficulty resides in the heterogeneity of terms used to describe the population. When looking to all areas of research pertaining to the needs of 'frail' older people and similar related terms such as oldest old, over 80's, vulnerable older adults and so on there is a huge variation in those actually investigated. In studies that do not offer a definition of frailty or use the term at all it is difficult to conclude that these are investigating a frail population. Although frailty increases with age, there are individuals in the older age groups who are not frail. Indeed, of community dwelling adults, 16% of those between 80 and 85 years and 26% of those over 85 years old could be classified as frail ¹ (Collard, Boter, Schoevers, & Oude Voshaar,

¹There was a wide range in estimated frailty which reflected the differences in how frailty was defined.

2012). Also identifying older people according to age may miss those in lower social economic groups for whom frailty may emerge earlier in life (Syddall et al., 2010). Therefore, studies that evaluate people together according to age could identify individuals whose situations may be very different.

1.3 Frailty

In considering frailty there is a need to clarify what the concept means and how it is defined for the purpose of the study. I will now provide an overview of frailty in the published literature which has expanded over recent years. I will begin with the use of the term and lack of consensus over what it actually means before outlining different definitions, models and criteria for identifying frail individuals. I will conclude by explaining how frailty was defined and operationalized at the outset of this study.

1.3.1 Use of the word frailty

The Oxford English dictionary describes frailty as 1: weak and delicate. 2: easily damaged or broken. However, the term frailty is often used within the health and social care community to describe older people who are vulnerable to a multitude of environmental stressors and are, therefore, at risk of worsened disability, morbidity and mortality. The term frailty has been described as an important concept in the care of older people and in ageing research (Bergman et al., 2007) and a survey of health care practitioners showed that 69% agreed that the term ‘frailty’ is clinically useful (Kaethler, Molnar, Mitchell, Soucie, & Man-Son-Hing, 2003). Similarly Clegg et al describe frailty as ‘a practical unifying notion in the care of elderly patients that directs attention away from organ specific diagnoses towards a more holistic viewpoint of the patient and their predicament.’ (Clegg, Young, Iliffe, Rikkert, & Rockwood, 2013: 381). However, a working definition of exactly what frailty is could help to identify frail individuals in order to understand their experiences and needs and provide care and support in ways that are meaningful and helpful for older people towards the end-of-life.

1.3.2 Lack of consensus surrounding frailty

Historically, frailty has been defined in an array of ways from simply describing those over 75 years of age, as older people with vulnerability secondary to physical or mental impairment or a definition based on whether an individual would benefit from an intervention or receipt of long-term care services, to becoming equated with disability, multimorbidity or simply ageing (Hogan, MacKnight, & Bergman, 2003). Although considerable overlap occurs between frailty, multimorbidity and disability, these concepts remain distinct from each other (Fried et al., 2001; Fried et al., 2004; Wong et al., 2010). Similarly frailty cannot be attributed purely to aging (Schuermans, Steverink, Lindenberg, Frieswijk, & Slaets, 2004; Rockwood et al., 2004).

Definitions of human frailty, as they apply to individuals in old age, have remained controversial (Fisher, 2005). For example, Ory et al., in a study of frailty and injuries (Frailty and Injuries: Co-operative Studies of Intervention Techniques [FICSIT]) describe frailty as ‘severely impaired strength, mobility, balance and endurance’ (Ory et al., 1993: 284) while Rockwood and Mitnitski define frailty as ‘a non-specific state of increasing risk, which reflects multi-system physiological change’ (Rockwood & Mitnitski, 2007: 722). Working groups of clinicians and researchers (European, Canadian and American geriatric advisory panel) have failed to reach a consensus on an operational definition of frailty despite having a clear understanding of the need for, and utility of a definition (Van Kan et al., 2008; Rodriguez-Maas et al., 2013). Difficulties arise when agreeing on the elements that constitute frailty however there is agreement on the conceptual framework of frailty as ‘a multidimensional syndrome characterized by decreased reserve and diminished resistance to stressors’ (Rodriguez-Maas et al., 2013: 65). On looking more closely at writings on frailty a divide emerges between theories based on the purely biomedical and those that include psychological and social elements. It is here that some describe the difficulty in defining frailty as residing in that what is attempted is to reach a broad definition as opposed to distinguishing between subsets of frailty (Morley et al., 2013). They make the distinction between defining frailty as a

condition of an individual compared to a medical syndrome of physical frailty defined as ‘A medical syndrome with multiple causes and contributors that is characterised by diminished strength, endurance, and reduced physiologic function that increases an individual’s vulnerability for developing increased dependency and/or death.’ (Morley et al., 2013: 4). Hogan et al describe attempts to understand frailty as separable into areas of models, definitions, and criteria for frailty; however, within these we can distinguish the above divide (Hogan et al., 2003).

What remains unclear is just how frailty, multimorbidities, disabilities and age contribute to each other given their overlapping nature. For example, while having several diseases increases the risk of becoming frail, causal direction is unclear (Levers, Estabrooks, & Ross Kerr, 2006). Furthermore, the relationship between quality of life and frailty has also been questioned as both relate to mortality (Gobbens, Luijkx, & van Assen, 2013).

1.3.3 Definitions of frailty

Definitions (that is statements aimed at clarifying and making explicit our understanding of something) of frailty may be based on vulnerability and the ability to withstand stressors or be based on actual disease states, thus following a biomedical understanding. Alternatively they may be underpinned by dependency with respect to the ability to carry out activities of daily living or instrumental activities of daily living, so integrating psychosocial elements. Within the research literature definitions may be conceptual, and these focus predominantly on physical domains. Alternatively they are operational, also heavily favouring physical but incorporating other criterion (Gobbens, Luijkx, Wijnen-Sponselee, & Schols, 2010c; Gobbens, Luijkx, Wijnen-Sponselee, & Schols, 2010a; Gobbens, Luijkx, Wijnen-Sponselee, & Schols, 2010b).

1.3.4 Models of frailty

Models (that is conceptual descriptions or analogies used to understand what is abstract or non-observable) of frailty may be mathematical in that they are based on probability of morbidity or mortality or on the counting of accumulating deficits.

Other models may rely simply on ageing, primary pathways such as muscle deterioration or multiple system dysfunction. Many authors take a unidimensional approach and describe sub-types of frailty, e.g. medical frailty, functional frailty, mental frailty and physical frailty (Jones, 1990; McNamee et al., 1999; Morley et al., 2013) with the implication being that an individual is characterized as frail according to one sub-type. In contrast Multidimensional approaches regard an individual as frail based on dimensions of frailty as follows: functional impairment and dependence on others for activities of daily living that threaten the ability of a person to live independently in the community; poor physical health such as chronic illness or acute illnesses; disability; vulnerability or lack of strength and resilience; poor mental health functioning; requiring formal, informal, or long-term care to meet basic needs; old age (Markle-Reid & Browne, 2003; Puts, Lips, & Deeg, 2005; Gobbens et al., 2010b; Gobbens, Luijckx, & van Assen, 2013; Rodriguez-Maas et al., 2013). Of note here, is the inclusion of psychosocial elements. In fact, different academic disciplines from medicine to anthropology employ different definitions based on their contrasting theoretical assumptions and understandings of the underlying causes, processes and dimensions of frailty and the relative importance that they place on the impact of social and environmental factors. More recently, frailty has been described as encompassing such domains as distinct components. A large study carried out in the Netherlands utilized the Tilburg Frailty Indicator (Gobbens, van Assen, Luijckx, Wijnen-Sponselee, & Schols, 2010) which distinguishes physical, psychological and spiritual frailty (van Campen & Ross, 2011). They described the various components of frailty as occurring heterogeneously across the group suggesting that, even when accounting for different aspects of the condition distinctly, frailty is not a homogenous and uniform situation for older people.

Looking more closely at specific disciplines, the medical and physical sciences reveal a number of conceptual models of frailty which generally involve physiological and pathological dimensions. These include descriptions of frailty according to disability (Campbell & Buchner, 1997), to function, that is the accumulation in deficits in the functional physical, nutritive, cognitive and sensory

domains (Strawbridge, Shema, Balfour, Higby, & Kaplan, 1998) or physics (Bortz, 1993) as a cycle (Walston & Fried, 1999) or a biological syndrome characterised by weight loss, exhaustion, inactivity, slowness and weakness (Fried et al., 2001). A dynamic model of frailty however, includes broader environmental factors such as the social environment in conceptualising frailty based on a balance of assets against deficits cumulating across the lifespan (Rockwood, Fox, Stolee, Robertson, & Beattie, 1994). Netherlands describes frailty according to sub types of physical, psychological and social (Campen & Ross, 2011).

Within the behavioural sciences a broader approach emerges which incorporates a combination of personal, including physical, psychological, cognitive, spiritual and environmental factors viewing frailty as a social construction (Raphael et al., 1994). The anthropological model of the social construction of frailty broadens still to include a societal element (Kaufman, 1994). This emphasises the lived experience of frailty with the practical and social activities of daily living viewed as reflections of society's views on ageing as a struggle to maintain independence in the face of impending dependency. This view states, that 'what we ask about frailty frames its definition.' In general, the behavioural science view of frailty is that it can be regarded as a social construction with frailty being constructed along a continuum opposite hardiness with relative frailty dependent on interacting environmental and personal factors.

Evidence that the importance of an inclusive biological, psychological and social approach is gaining acceptance can be seen in recommendations for a successful definition of frailty which advocate that an 'integrative and comprehensive approach would include biological, clinical (including cognition), psychological, social, and environmental components which interact across a person's life span, displaying or promoting the emergence of frailty' (Hogan et al., 2003: 20). Similarly Gobbens et al cite the need for an integral model of frailty that incorporates not just physical but psychological and social domains and highlight the impact that such dimensions have on predicting outcomes over and above physical frailty as corroborating its multidimensional nature (Gobbens, Luijkx, Wijnen-Sponselee, & Schols, 2010).

They proposed the domains of physical, psychological and social frailty as interrelated but distinct (Kelaiditi et al., 2013; Gobbens et al., 2010) an approach utilized in a study of frail older people in the Netherlands (van Campen & Ross, 2011).

1.3.5 Criteria for frailty

In looking at criteria (that is the traits characteristic of a defined entity) those articulated for frailty are too vast to summarize here with 30 of such being described by Hogan et al (Hogan et al., 2003). Accordingly, the focus for this study will remain on those that have attempted to provide predictive outcome measures as these will have the most obvious utility in identifying people to be included in an end-of-life study. The largely biomedical ‘phenotype’ and ‘deficit accumulation’ approaches have attempted to identify individuals as frail and to provide predictive outcome measures. Fried et al describe a possible phenotype of frailty, where five items are articulated and a person is considered frail once they exhibit three out of five set items of weakness, exhaustion, slowness, weight loss, and reduced physical activity (Fried et al., 2001). The ‘phenotype’ approach is claimed to correlate better with probability of institutionalisation or survival better than age. The accumulation of deficits measure, on the other hand, counts the number of things that someone has wrong with them including symptoms, diseases and disabilities, rather than looking at specific items, and proposes a frailty index based on the count (Rockwood & Mitnitski, 2007; Mitnitski, Mogilner, & Rockwood, 2001; Rockwood & Mitnitski, 2007). The authors conclude that deficits accumulate steadily in relation to increasing age with the number of deficits predicting five year mortality better than age. In comparison, deficit accumulation (Frailty Index) and phenotype approaches were found to show considerable convergence with each other (Rockwood, Andrew, & Mitnitski, 2007; Rockwood et al., 2007). In a comparison of eight different frailty scales Theou et al concluded that the ‘Frailty Index seems to be a feasible scale that captures the multidimensionality of frailty and has high predictive value’ (Theou, Brothers, Mitnitski, & Rockwood, 2013: p1543). Although the frailty index has been criticised for the inclusion of disability, and disability and frailty are not the same

thing, frail older people experience greater levels of disability the nearer they are to death. Accordingly the frailty index is a better predictor of mortality than the phenotype approach (Mitnitski et al., 2001).

In the absence of ‘predictive’ criteria that include psychological and social measures, the formulation of a ‘global clinical measure’, (Rockwood et al., 2005) appears to best approximate the approach to frailty articulated in the behavioural sciences. Fitness and frailty in older people was estimated by physicians’ clinical judgement, rating older people on a scale of one (very fit) to seven (severely frail). Such clinical judgement was found to predict institutionalisation and survival as well as the Frailty Index of the deficit accumulation approach (See appendix 12).

It appears, then, that frailty cannot easily be defined, conceptualised or set criteria stated arguably because it is primarily a concept which is constructed socially. As such, the social world is described as constructed by those who live in it and cannot be without reference to context. Individuals are regarded as creating their realities through the processes of interaction, conversation and comparison with others (Crossley, 2000). More specifically, interpretations of health and illness are explained as only making sense in relation to particular social and cultural contexts and remain obscure if we attempt to isolate them from or treat them independently of such contexts (Crossley, 2000).

This socially constructed approach appears to resonate in the practical utility of what occurs in hospital wards and care units with the clinical frailty scale (Rockwood et al., 2005) more closely resembling the real life situation of how frailty is pragmatically defined. In attempting to identify frail older individuals approaching the end of life, there is a certain ecological sense in asking the opinions of the clinicians involved especially given that this correlates well with other, more complex and quantitative tools aimed at measuring frailty and predicting mortality and the need for institutional care.

1.3.6 An operational definition of frailty for the current study

For the purpose of this study, frail older people were identified according to the 'global clinical measure'. An operational definition conceptualised frailty as a socially constructed entity, that exists for the individual rather than just within him as a quality and a dynamic process involving the person and their broad social environment, including health care professionals, emerging at the tipping point between social and functional dependence and independence (Kaufman, 1994).

1.3.7 Palliative and end-of-life care for frail older people?

So what understanding do we have of the care needs of frail older people as they approach the end of life? Given that death occurs as a process it is helpful to explore this last phase of life as it changes over time. Looking temporally at both retrospective and prospective views, older adults with cancer, congestive heart failure or coronary heart disease were asked about the treatment choices they had made in the past and their treatment preferences for the future (Fried & Bradley, 2003). Preferences were reported as changing over time. Rigby, Payne and Froggat discuss the broad environmental needs of older adults towards the end-of-life, specifically pointing to social and spiritual needs as well as the physical environment also noting how these needs are not static but may change over time (Rigby, Payne, & Froggatt, 2010).

Another focus of temporally based research has looked at advance care planning in attempting to ask people to project ahead what their end-of-life preferences will be and is considered good practice in palliative care. Lorenz and colleagues cite evidence that patients wish to discuss end-of-life issues and advanced directives with medical professionals (Lorenz, Rosenfeld, & Wenger, 2007), however, research specifically investigating older adults is more ambiguous. An interview study of elderly housebound chronically ill older people found participants to be unwilling to talk about death and dying with a tendency to sidestep the issue or make more existential claims such as a desire to simply take one day at a time (Carrese, Mullaney, Faden, & Finucane, 2002). The authors describe participants as holding a

world view that does not easily allow for advance care planning. Participants planned for death, with regard to the actual moment of death and to its aftermath, but simply did not wish to think about the process of dying until they were actually in that situation and hope of survival was lost.

Similarly, a focus group study examining older adults' thoughts and understandings of life prolonging and basic care technologies used in end-of-life care found discomfort in discussing advance care plans (Seymour, 2003). Participants were uneasy with such advance care documents due to the possibility that they may change their minds. However, those in the older adult population willing to discuss end-of-life options described difficulties in engaging family members in such discussions. They also talked of their concerns around dying alone, poor care or pain, having little say in where they die and confusion around terminology such as advance care planning and advance directives (Clarke & Seymour, 2010).

Lloyd-Williams et al found that community dwelling older adults did consider issues surrounding death and dying, specifically getting one's affairs in order and pre-planning funerals so as to avoid burdening loved ones (Lloyd-Williams, Kennedy, Sixsmith, & Sixsmith, 2007). However, they also expressed fears of how death may occur. Specifically they feared debilitating illness necessitating full time care or care home residence rather than death itself. Taking a more circumspect approach, Vig and colleagues asked older adults with cancer or coronary heart disease about what they considered to be a 'good or bad death' (Vig, Davenport, & Pearlman, 2002). They found heterogeneous answers that reflected a wide range of individual circumstances suggesting a need to look in more detail at experiences within the situational contexts of older people lives. A report surrounding end-of-life care for older people, which would include frail individuals, described a paucity of knowledge regarding the experiences of older adults towards the end-of-life (Seymour, Witherspoon, Gott, Ross, & Payne, 2005).

Much difficulty for frail older people, however, resides in the manner in which they reach the end of life. As Nicholson (Nicholson, 2009b) points out they frequently remain outside the social and clinical care frameworks as they are not obviously dying, whilst there is a tendency for older peoples' care to become reactive rather than anticipatory (Hanratty et al., 2012). Furthermore, their deaths may be regarded as expected and thus what Bailey et al describe as 'subtacular' suggesting the opposite of spectacular (Bailey, Murphy, & Porock, 2011). Frail older people also frequently experience multiple transitions between places and institutions towards the end of life, with attendant problems of poor communication between and even within settings (Hanratty et al., 2012).

1.4 Changing needs over time towards the end of life: Trajectories

An alternative approach to understanding how needs may change over time towards the end of life is to consider archetypical trajectories of change. Following the original descriptions of dying trajectories of Glaser and Struass (Glaser & Strauss, 1968) and looking longitudinally, Lunney et al described three typical physical end-of-life routes or trajectories omitting that of a sudden death (Lunney, Lynn, Foley, Lipson, & Guralnik, 2003). These are:

1. Death following acute and relatively predictable, typically cancer as *fig 3* shows.
2. Death following gradual decline with intermittent exacerbations, typically organ failure as *fig 4* shows.
3. Death following a gradual more prolonged dwindling, classically frailty or dementia and decline with death occurring in the latter after a period of what can be years as *fig 5* shows.

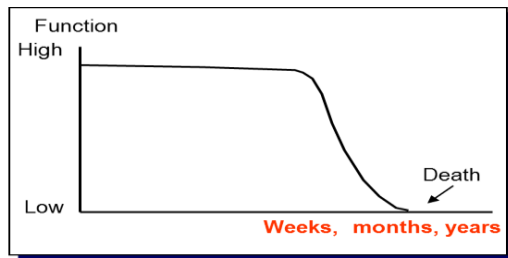


Fig 3: Typical dying trajectory of cancer

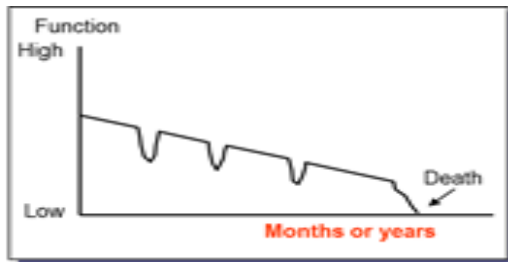


Fig 4: Typical dying trajectory of organ failure

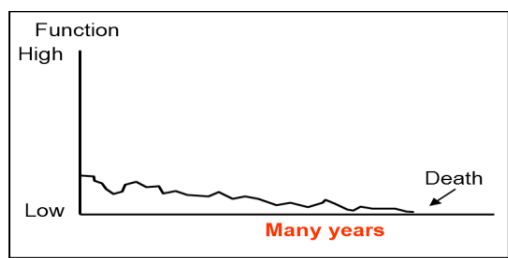


Fig 5: Typical dying trajectory of frailty and dementia

Reproduced with thanks. (Murray, Kendall, Boyd, & Sheikh, 2005)

1.5 Palliative care dimensions

The above trajectories describe physical function yet palliative care emphasizes that dying is a four-dimensional activity: physical, psychological, social and spiritual or existential (Davies & Higginson, 2004). Physical needs may include increasing levels of dependence on activities of daily living (ADLs), specific symptoms such as pain, breathlessness or falls. Psychological needs can include anxiety, depression or life satisfaction while social needs involve interactions and relationships with others, be it via contact or involvement in the world broadly or with friends and family. Existential or spiritual needs involve a person's sense of meaning and purpose in life,

may or may not include a religious faith or orientation and vary widely between individuals. These dimensions can be closely intertwined and distinctions between them can be difficult to draw (Murray et al., 2007); however, bringing together these different aspects Cicely Saunders, describes multidimensional suffering as ‘total pain’ (Saunders, 1996).

Exploring end-of-life trajectories according to these palliative dimensions using 112 serial in-depth interviews with people with end stage lung cancer or heart disease Murray et al found that psychological, spiritual or existential and social trajectories do not clearly correspond to the physical trajectory but can change according to other factors (Murray et al., 2007). For example, psychological and spiritual distress related to specific trigger points such as being given a terminal diagnosis or discharge from hospital for cancer patients (*fig 6*) where such distress tended to mirror acute exacerbations for heart failure patients. Social distress or decline also occurred differentially with a sharp drop off in social interactions signalling a ‘social death’ for cancer patients, when their physical decline became more acute.

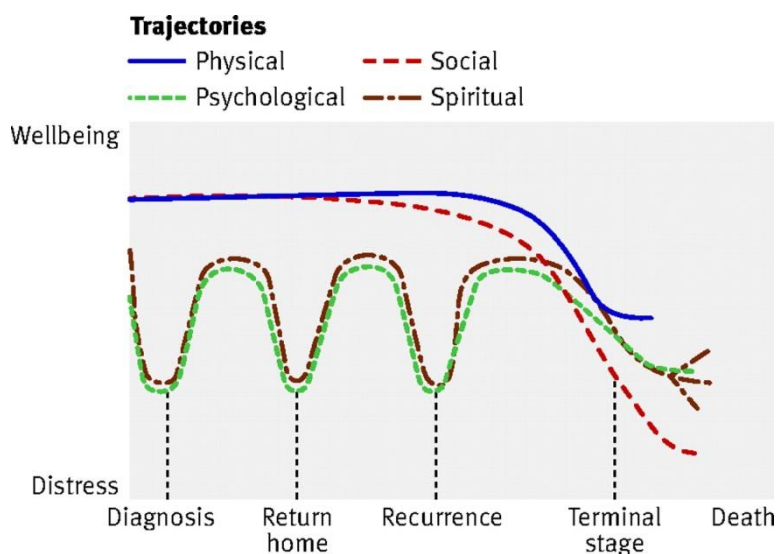


Fig 6: multidimensional trajectories in lung cancer

Serial interviews with people with organ failure have also revealed that at times of acute physical deterioration there may also typically be psychological and social distress (*fig 7*).

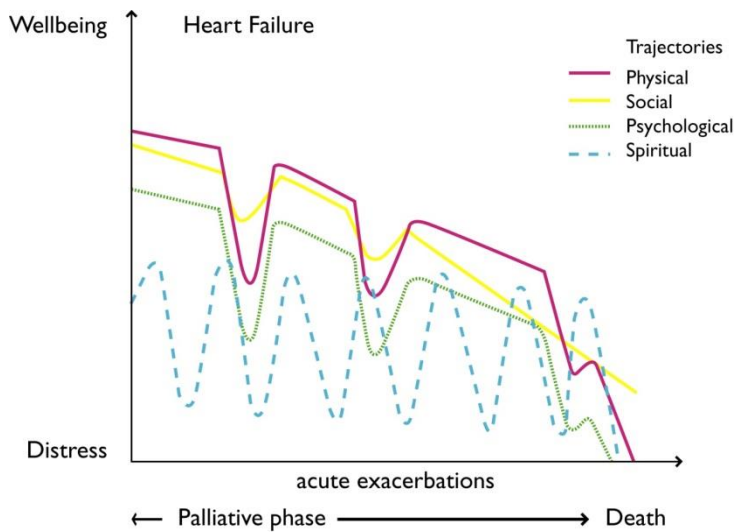


Fig 7: multidimensional trajectories in heart failure

Figures reproduced with thanks from Murray et al 2007 Journal of Pain and Symptom Management.

1.6 Conclusion

There remains an opportunity to look longitudinally at the lives of frail older adults as they approach the end of life in order to explore if typical multidimensional trajectories can be described and to identify when specific aspects of need change in order to aid anticipatory care and planning.

Holistic and dynamic information of this nature could help to guide policy and interventions to provide timely ‘whole person’ care for dying individuals as they are better able to suggest when to implement care strategies based on palliative care dimensions at times of need. It is important, then, to understand these aspects of need and how they may change or interact over time in order to evaluate how or indeed if developing a palliative approach to the care of frail older people towards the end-of-life is the most effective way forward at this time.

Chapter 2: Frailty towards the end-of-life: A Review of the Literature

2.1 Introduction:

In this chapter I will describe the literature surrounding end-of-life needs and experiences for frail older people. I will begin by outlining broad areas of research before presenting a focused literature review of longitudinal studies involving frail older people towards the end-of-life. I will follow by discussing cross-sectional literature involving non-physical dimensions of need in frailty and bring in qualitative studies looking at potentially similar populations. Finally, I will describe what is missing in terms of our understanding of the needs and experiences of frail older people towards the end of life in order to consider how qualitative longitudinal research may help inform the field.

2.2 Aim:

The purpose of this review is to investigate current knowledge in order to provide a narrative overview (Green, Johnson, & Adams, 2006) of physical, social, psychological and existential experiences and needs towards the end of life of community dwelling, as opposed to institutionalized older adults defined as frail. This specific focus was taken in order to identify only those studies relevant to individuals in the community on the frailty trajectory. I have also focused on studies of cognitively intact people as I considered that people with dementia may have very different needs and experiences to those without. Again, the population prevalence of dementia is considered to be 20-30% of 80 year olds and 50% of 90 year olds (Ferri et al., 2006) and while cognitive function decreases with increasing frailty (Buchman, Boyle, Wilson, Tang, & Bennett, 2007) there is likely to be a sizeable proportion of older adults nearing the end-of-life without significant cognitive impairment. Furthermore, although many frail older adults may reside in nursing or care homes they are likely to have their needs met, or otherwise, quite distinctly from those living in the community. I will begin by outlining longitudinal research for

each of the palliative care dimensions and will focus on research where a justification for how participants are classified as frail is given. I will also incorporate cross sectional literature regarding frailty and palliative care dimensions.

2.3 Methods:

MEDLINE, PsycINFO, Embase, CINAHL and Web of Science databases were searched (1990-2012) using key words groupings to identify longitudinal studies that could describe palliative care dimensions of need over time for frail older people.

These were:

- 1 'frail*' or 'over 80' or 'older adults' and
- 2 'longitudinal' or 'retrospective' or 'prospective' and
- 3 'palliative care' or 'end of life'

Studies focusing on individuals with dementia or cognitive impairment were excluded as I considered that these people may have very different needs and experiences to those who are cognitively intact. Also excluded were studies focusing on specific illness such as heart disease or cancer.

2.4 Results:

199 abstracts were identified. Empirical longitudinal studies that focused on frail or aged participants were selected and full texts reviewed. Of those, only studies that specifically offered a definition of frailty were included. See figure 8 for details of the selection.

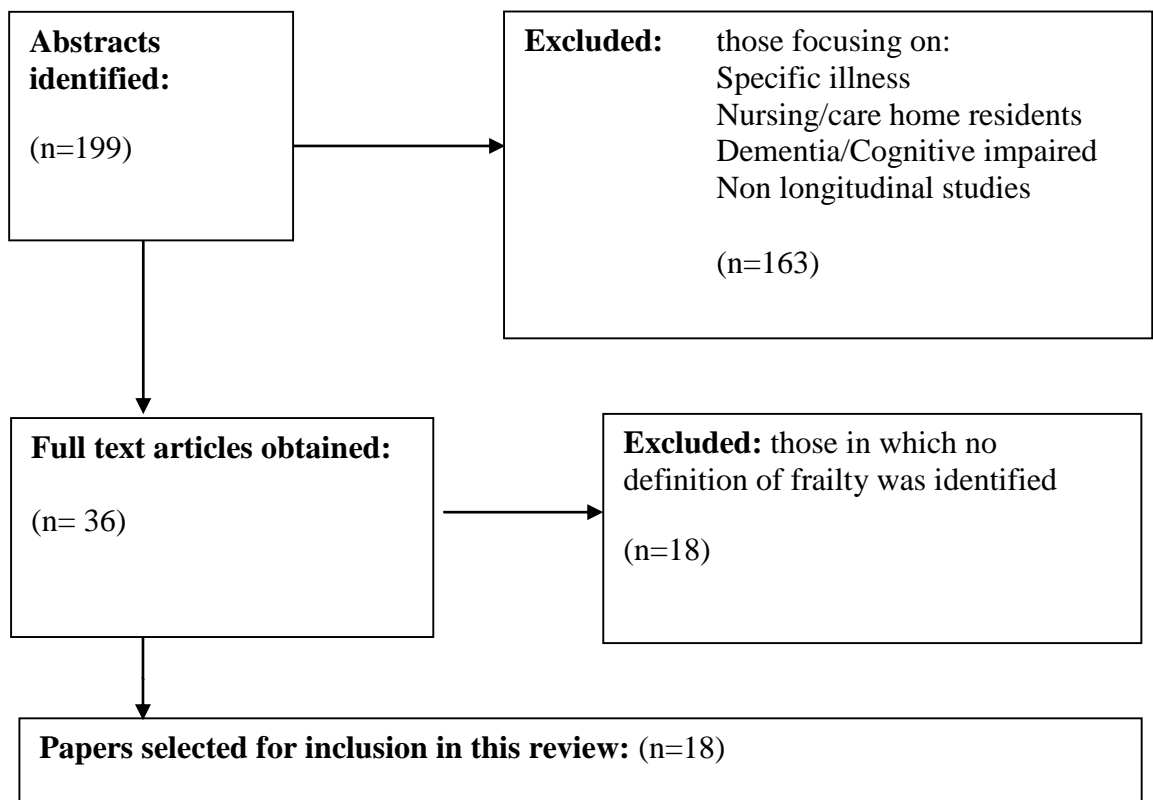


Fig 8: Flow chart for selection process

18 relevant reports were identified (table 1). These were grouped according to the dimension that they most pertained to and are considered below.

Author	Definition of frailty	Length of follow up	Outcomes or measures	Setting of study	Participants
Lunney et al 2003	Those who had reported a nursing home stay	Last 12 months of life of decedents	Interviews surrounding ADL dependence that were completed 1 year before death.	4 regions across USA EPESE study	N= 4190. Mean Age 81. Range 65 years and over .of which 837 were frail. Mean age 85.
Covinsky et al 2003	Eligibility for PACE and dependent on at least one ADL	2 years retrospective from death	3 monthly interviews of functional dependence on bathing, eating and mobility. Degree of incontinence	Assessed at enrolment to PACE: PACE enrolees over 13 sites. USA	N= 917. Mean age 81 to 85 years at death
Li et al 2005	Eligibility for nursing home placement	2 years	Nurse based assessment of ADL disability via MDS-HC scale.	Home and Community-Based Medicaid Waiver Program participants. Michigan USA	N= 3161. Mean age 78 Range 65 years and over
Hardy et al 2005	Slow gait speed	Median 60 months	Nurse assessment of frailty at baseline and every 18 months. Monthly telephone assessments of degree of disability across 4 ADL measures.	Members of a large Health plan Connecticut USA	N= 332 frail. Mean age 80. 432 non-frail participants. Mean age 77
Gill and Kurland 2003	Slow gait speed	2 years	Nurse assessment of self-reported diagnosed illness. Follow up telephone interviews of ADL disability	Members of a large Health plan Connecticut USA	N= 332 frail. Mean age 80. 432 non- frail. Mean age 77

Gill et al 2006	Adapted version of Frailty Phenotype	Up to 54 months	Nurse assessment of number of frailty characteristics via the Fried criteria	Members of a large Health plan Connecticut USA	N= 752 of which 194 frail, 386 pre frail, 172 non frail. Mean age 78
Gill et al 2010	Adapted version of Frailty Phenotype	Up to 108 months	Home assessments including disabilities in ADLs	Assessed in own homes: Members of a large Health plan Connecticut USA	N= 383 decedents of a larger group of 754 initially independent participants. 107 frail. Mean age 84.4.
Jacobs et al 2011	Adapted version of the Frailty Phenotype	Assessed after 15 years	ADL dependence, sensory impairment, depression, self-rated health	Jerusalem Longitudinal cohort study Israel	N= 840: 164 frail, 470 pre-frail, 206 non frail. Age 70 at baseline 85 years at follow-up.
Espinoza Jung and Hazuda 2012	Frailty phenotype 3 of 5 characteristics	Up to 9 yrs 8 months	Frailty transitions: Changes in number of frailty characteristics or death.	Assessed in own homes: San Antonio Longitudinal Study of Ageing USA	N= 597 of which 52 frail, 17 pre-frail 228 non frail. Mean Age 69.6. Range 65-80 years
Izawa et al 2010	Entitlement entry into a long term care insurance program and provision of home care services.	2 years	ADL via Barthel Index Hospitalisation and falls	Assessed in own homes: Nagoya longitudinal study of the frail elderly Japan	N= 543. Mean age 80. Age range from which sample was drawn 65-102 years.
Guilley et al 2008	Deficiencies in at least 2 of the health domains	12 – 18 months for 5 years.	Self-reported deficiencies in 5 health domains.	Swiss Interdisciplinary study on the oldest old.	N= 339. Mean age 81.9. Range 80 -84 years.
Sands et al 2006	Eligibility for PACE and dependent on at	6 weeks prior and 6 and 12 weeks after	Unmet and met need via levels of formal and informal help in relation to	13 PACE sights	N= 2943. Mean age 79. Range 65 years and over.

	least one ADL	PACE enrol	ADL dependency		
Miller and McFall 1991	Inability to carry out one or more personal care or personal management activity for at least 3 months	2 years	Caregivers' perceived personal and interpersonal burden at baseline. Later changes in use of formal and informal help, ADL, IADL, hospitalisation and chronic conditions. Institutionalisation and mortality.	National long term care survey USA	N= 664. Mean age 78.5. Range 65 years and over.
Landi et al 2004	Via the Minimum Data Set - Home Care tool	12 months	Hospitalisation, MDS-HC (including ADLs and cognitive status), Social living' circumstances	National Home Care Program Italy (SNHCP)	N= 1291. Mean age 74.5. 62% over 75 years.
Mor-Barak, Miller and Syme 1991	Nursing home eligibility	Up to 2 years	Self-rated health. Life events (Geriatric readjustment rating scale), Social Networks (Lubben Social Network Scale)	Multi-purpose senior services project California USA	N= 3559. Mean age 78. Range 65 years and over.
Kuzuya et al 2006	As Izawa	Up to 36 months	ADLs, Day care attendance and other service use.	Community Based Japan	N= 1673. Mean age 80. Range 65 years and over
Yaffe et al 2003	PACE enrolees	6, 12 and 18 months	GDS scores Dependency level on 7 ADLs	Clinical setting at enrolment to PACE. USA	N= 250. Mean age 78-80

Nicholson et al 2012	Immediate care team assessment as being of advanced age, vulnerable and dependent.	17 months	Repeated in-depth qualitative interviews using psychosocial approaches to elicit participant narratives	Own Homes UK	N= 17. Aged between 86 and 102.
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Table 1: Papers included in the narrative literature review

Abbreviations

ADL –Activities of Daily Living

IADL – Instrumental Activities of Daily Living

MDS-HC – Minimum Data Set for Home Care

GDS – Geriatric Depression Scale

SNHCP – Silver Network Home Care Programme

PACE – Programme for All-Inclusive Care

2.4.1 Physical dimensions – function and dependency

The earliest study by Lunney et al used interviews surrounding physical dependence on seven activities of daily living (ADLs) and compared data on the last 12 months for those that died (Lunney et al., 2003). Frail people were described as being more disabled in the last year of life than those with organ disease or cancer and as showing a pattern of gradual decline with modest acceleration towards the end. Similarly Covinsky et al investigated functional trajectories over the last 2 years of life (Covinsky, Eng, Lui, Sands, & Yaffe, 2003). Dependence levels across three functional measures were assessed every three months retrospectively from death. The authors described a long, steady increase in functional dependency with a slight acceleration apparent in the final year. However, they noted only a slight acceleration in dependence ‘as death approached’, finding no obvious point which signalled a terminal phase.

Shortly after these two studies were published, Li et al explored trajectories of ADL disabilities of over 3000 older people (Li, 2005a). They showed that ADL capacity for those that died or were institutionalized declined, gradually followed by a plateau period, then a steep decline in the final few months before death. Li et al also described a great deal of individual variation in trajectories even in those close to death. However, the large numbers in the study facilitated statistical significance to the average trajectories described. The author claimed these as contradictory findings to Covinsky’s. However, Li et al used a severity of disability measure, and included a wider range of ADLs. Covinsky also excluded individuals that were fully dependent

two years prior to death, which may have resulted in a higher functioning group at the outset. Inclusion of dependent participants could account for Li's plateau and the more gradual decline observed.

A study also published in 2005 by Hardy et al looked at levels of disability and independence of initially ADL independent adults over 70 years old including a subgroup of frail older adults (Hardy, Dubin, Holford, & Gill, 2005). Monthly telephone assessments revealed participants as non-disabled, mildly disabled or severely disabled according to their requirement for help over four ADLs. Frailty was also measured every 18 months. Over 57 months, frail participants experienced an average of six transitions between states of disability although there was a wide range between participants of between one and 30 transitions. Overall, frail individuals were found to spend more time in states of disability and to have more individual episodes of disability. The authors claimed that their study supported a theory of 'unstable disability' and concurred with Covinsky's findings of a slow progressive decline in frail individuals. They also found substantial variation between individuals similar to Li's plateau and variation in trajectories, stating, "on an individual level, however, we identified substantial variation in trajectories to death even among frail participants, ranging from death without reporting disability in the previous month to death after several years of continuous disability." (Hardy et al., 2005: 580). They further described observing all of Lunney et al's three end-of-life trajectories within the frail group and that 20% of frail individuals remained independent.

Part of the same research group as Hardy et al, Gill and Kurland used the same participants and also concluded that 44% of frail older people had multiple months or episodes of disability with 12% being disabled in at least half of all months (Gill & Kurland, 2003). They described 'persistent, chronic and severe disability' for frail participants yet no single pattern of disability experience emerged across the 24 months for those that had died or those that survived. Gill et al further looked at degrees of frailty showing frailty as increasing over time with frail individuals being at a 3 to 5 fold increased risk of dying, compared to those that were not frail (Gill,

Gahbauer, Allore, & Han, 2006). However, they also highlighted the possibility for people to become less frail for periods. Further investigation of ADL trajectories in the last year of life, mapped to the condition leading to death, found no predictable trajectory for frail older adults even though frailty was the most common condition leading to death (Gill, Gahbauer, Han, & Allore, 2010). Indeed, this study also describes a great deal of heterogeneity in the disability trajectories at the end of life.

While Gill's and Hardy's conclusions appear contradictory to those of Lunney et al, it should be noted that the latter's frailty definition involved having a nursing home stay at any given point possibly selecting out higher functioning individuals and over sampling the cognitively impaired. Given Covinsky's description of a disparate trajectory for cognitively impaired individuals, this may account, at least in part, for the differing patterns of decline. Such an effect could be illustrated by Jacobs et al who looked at frailty, cognitive impairment and mortality including cognitively impaired, frail and non-frail older people (Jacobs, Cohen, Ein-Mor, Maaravi, & Stessman, 2011). Across measures of ADL dependence, sensory impairment, depression and self-rated health, frail individuals were found to fare markedly worse than non-frail. Additionally, frailty, rather than cognitive impairment was the most significant indicator of mortality. However, Gill and Hardy acknowledge that, selecting initially non-disabled participants may have influenced their results. So, potentially including more individuals with cognitive impairment and initially disabled individuals may account for Lunney and Lynn's less fluctuating physical trajectory. Finally, the varying time scales may impact upon conclusions drawn. Lunney and Lynn looked at the 12 months prior to death, whereas the Gill and Hardy studies varied from 24 to 108 months, and Covinsky, the last two years of life. Finally the size of the samples between the studies also varied with Lunney and Lynn describing outcomes for nearly twice as many frail older people as in the Gill and Hardy studies.

A more recent study investigated transitions between frailty states using measures including walking speed, grip strength, physical activity, exhaustion and weight loss (Espinoza, Jung, & Hazuda, 2012). Participants were graded by number of zero to

five frailty characteristics and followed across a range from two months to nine years and eight months. Of those designated as frail at any level at baseline, the dominant transition was to death. However, similar to descriptions of the capacity for some individuals to improve in the above studies, they found 32.4% of participants with three frailty characteristics at baseline showed an improvement in frailty, this being rare for those with four or five characteristics. Interestingly, they found that a transition to death was nearly twice as likely for those whose frailty measures were performance based (walking speed, grip strength) or based on low physical activity than those based on self-report measures (exhaustion, weight loss). What is not clear from this, however, is whether this is because of the measurement or the measure. Grip strength and walking speed were assessed objectively while other measures were assessed via self-reported questionnaire. Given that self-report measures are likely to be influenced by varying factors including a respondent's desire to provide a positive self-image, which may be even more acute in a telephone interview and a potential for response shifts in evaluating one's own disabilities, these may variably reflect physical function. Additionally, walking speed and grip strength may indicate underlying physical weakening that is less obvious to the participant themselves.

Hospitalization can mark a significant point in an end-of-life trajectory. Izawa et al provided data on hospitalization and falls in relation to changes in ADL dependency as part of a larger longitudinal study of frail older people (Izawa et al., 2010). Similar to previous descriptions of a plateau period and the potential for some participants to improve, they found that 77% of participants maintained or improved their dependency level while 23% declined over two years. Rates of hospitalization and falls were higher for the latter group than the former highlighting the negative outcomes related to declining ADL independence. This study may suggest that there is a group of more impaired frail individuals for who decline to death is likely following increasing dependence. However, the possibility of a bi-directional association between hospitalization and degree of frailty should be considered as was suggested in further analysis from previous work of Gill et al which highlighted the association between hospitalizations and worsening frailty states (Gill, Gahbauer, Han, & Allore, 2011).

Guilley et al looked at dynamics of frailty and ADL dependence, self-reported deficiencies in mobility, sensory, energy, physical pain and memory health domains for up to five years (Guilley et al., 2008). Those with deficiencies in two or more out of five health domains were considered frail and had a fourfold increase risk of ADL dependence over 12 to 18 months and three fold risk of death within five years. However, they found that deficiencies in specific domains of sensory, memory or energy were associated with poorer outcomes independently of problems with physical pain or mobility difficulties. They describe a pattern of transition from robustness through a prolonged period of ADL independent frailty to dependent frailty with occasional short lived periods of improvement possible, consistent with Fried et al's description of ADL dependence occurring, for these individuals, as a consequence rather than a cause of frailty (Fried, Ferrucci, Darer, Williamson, & Anderson, 2004). However, authors point out that at any given time point, those that subsequently died were as likely to be independent and frail as dependent. This may involve death from causes on the other trajectories such as organ disease or cancers and that perhaps indicates those dying on the frail trajectory are those that become more dependent and physically weakened.

Guilley's findings appear consistent with the previous studies describing a plateau period (Li, 2005a; Izawa et al., 2010) a wide variation in possible individual trajectories (Hardy et al., 2005; Li, 2005a) the potential for periods of improvement (Espinoza et al., 2012; Izawa et al., 2010) and a period of increased frailty involving a faster decline towards death (Izawa et al., 2010). However, it should be noted that there is considerable heterogeneity between the studies' methods. In particular, self-reports may well offer publically acceptable versions of self-function and are possibly influenced by response shifts where individuals may feel more able, with the help of a new mobility aid for example, but may be physically worse. Moreover, conclusions also highlight that looking simply to indicators of physical decline as markers or triggers for introducing palliative care may be unhelpful for this group.

Moving on to look at the effect of meeting the ADL needs of dependent frail people a further investigation, from the same group of Program for All-Inclusive Care

(PACE) enrollees in the Covinsky study described earlier, was carried out by Sands et al (Sands et al., 2006). Rates of acute admissions to hospitals were retrospectively measured for the six weeks prior to enrolment in PACE and compared with rates six weeks and then twelve weeks after enrolment. Those with unmet ADL needs prior to enrolment had higher rates of acute hospital admissions compared to those whose needs were considered as met. Following enrolment in PACE, acute admissions reduced drastically at six and twelve weeks for both groups with levels becoming similar for those who had previously had their needs met as those who had not. This suggests that PACE services significantly reduce acute hospitalizations of frail older people and persists after controlling for baseline differences. The authors conclude that ‘there are potential health consequences of living with unmet ADL needs but that meeting disabled older peoples’ unmet needs can resolve these health consequences.’

Looking across the studies the methods of assessment varied. Espinoza used a mixture of self-report and objective measures via face to face evaluation; Covinsky used professional assessments; Li used face to face professional interviews and the Hardy and Gill group used nurse assessments for frailty measures and telephone interviews to gain ADL information. Also, the ADL measure used varied between studies. Lunney and Lynn addressed seven ADLs, Li used eight ADLs, Gill and Hardy used four physical that were activity based while Covinsky used three plus incontinence. Perhaps, then, different findings would emerge were performance based, rather than self-report, measures primarily used.

2.4.2 Social dimensions

Looking to social aspects of end-of-life trajectories of frail older adults, Miller and McFall carried out a study which investigated the effect of caregivers’ burden on frail older peoples’ changing use of formal helpers (Miller & McFall, 1991). Caregivers’ perceived personal and interpersonal burden was assessed at baseline and the interaction between this and later use of formal help was evaluated. Use of formal help increased over the period, in that those that did have formal help tended

to use progressively more over time. However, use and non-use of formal help was stable over time, meaning that those that used none tended to continue not using it while those that did tended also to continue to do so. A further association was found between use of formal help and increasing rates of institutionalisation and mortality suggesting that such help did not 'forestall institutionalization of community dwellers with high impairment'. Unsurprisingly, the authors found that recent hospitalization and increasing limitations in ADL and IADL capacity was associated with increased use of formal help over time. However, increasing numbers of chronic conditions was not an indicator of more formal help. By comparing high versus low burden groups, the authors showed that higher perceived personal burden and not interpersonal burden predicted use of increased formal help. This suggests that the carers' perceived interactional difficulties did not affect how much formal help was then used but that the caregivers' perceived burden was more relevant. Whether the personal burden felt by carers reflected increasing need of the older person or an evaluative change on the part of the caregiver the result may well affect the social circumstances and practical care of the older person.

An investigation of the effects of social factors and co-morbidity in relation to the hospitalisation of frail elderly people by Landi et al used a geriatric assessment tool, the Minimum Data Set for Home Care (MDS-HC), to provide information on a wide range of socio-demographic and clinical items (Landi et al., 2004). Living alone without an informal carer, previous hospital admission, five or more co morbidities or economic hardship was significantly and independently related to increased risk of hospitalisation. An earlier study considering social aspects as applied to financially poor frail older people was carried out by assessing health status, family situation and mental acuity (Mor-Barak, Miller, & Syme, 1991). Mor-Barak et al described social networks as relating to better health and major life events to worse health in their participants concluding that even after controlling for potentially confounding baseline characteristics such as poor self-rated health and objective health measures, social networks could buffer against the negative impact of major life events on the health of frail older people. It may be this very lack of a social 'buffer' that led to the more negative outcomes of those living alone in Landi's study.

Including other forms of social environment for older people, Kuzuya et al investigated the effects of day care use in relation to mortality. They described a reduction in mortality of 44-63% over a 21 month period for those that attended a day care centre at least twice weekly (Kuzuya et al., 2006). The effect was independent of sex, age and co-morbid conditions or diseases. However, as age, co-morbidities and depression decreased there was a corresponding increase in the protective effect indicating that the average benefit may be attenuated to those individuals rather than a generalizable benefit across the whole group. This is perhaps pointed at given the lack of effect of day care use for the 391 participants that had incomplete Geriatric Depression Scale (GDS) scores (25.6% of whom died compared to 13.1% of those with complete GDS scores) who had greater ADL disability, co morbidities, higher dementia and more cardiovascular disease.

2.4.3 Psychological dimensions

From the point of view of psychological morbidity, Yaffe et al investigated depressive symptoms finding that frail older women who had depressive symptoms at baseline had a significantly increased risk of death at eighteen months compared to those that had few or no depressive symptoms (Yaffe, Edwards, Covinsky, Lui, & Eng, 2003). The effect remains possible for frail older men; however, the small number of males in the study may have limited its power to detect a statistically significant outcome.

2.4.4 Psychological and existential dimensions

This interestingly highlights the interrelations between different dimensions. This was addressed in the only study involving defined, frail older people with respect to psychological and existential aspects (Nicholson, Meyer, Flatley, Holman, & Lowton, 2012). Twenty four qualitative interviews with 17 participants explored how participants responded to frailty over 18 months. Physical losses brought a 'sense of change, both in how participants saw themselves and in relation to how others saw them.' For some this was experienced gradually but for others in a more sudden manner following specific events. The frail older participants were also seen

as aiming to maintain control over their changing physical and social circumstances by remaining in their own homes yet needed to find new ways to be themselves within this environment. Participants were regarded as creatively using every day routines and rituals and constructing their own personal scripts to root themselves to their worlds and create balance. Frailty was regarded as a state of ambiguity and imbalance. Finally, participants were described as existing in the spaces between dependence and independence, between health care and social care and between active living and clinically recognized dying with functional and social losses facilitating an ‘understanding that life was coming to an end.’ However, the authors concluded that the timescale was too short to elicit more than small changes in the older persons’ circumstances and certainly there is no description of participants having died or moved into a nursing or care home.

2.5 Discussion of the focused narrative review

By reviewing the evidence of physical, social, psychological and existential dimensions of experience for frail older people towards the end of life, most data related to physical dimensions. In general, a pattern emerged of a gradual decrease in ADL capacity and increasing frailty leading to a more rapid decline towards death. However, when looking at groups that were initially classified as ADL independent there appears to be more fluctuation with less impaired individuals remaining within a stable plateau period, often maintaining their independence and showing the potential for short lived periods of improvement.

What also emerges, however, is a wide degree of variation between individuals even towards death and recognition that frailty is not simply unidirectional. In contrast to organ failure or cancer end-of-life trajectories this is an important difference. However there are indications that there may be a tipping point at which decline becomes inevitable. Additionally, meeting the physical needs of impaired individuals may alter outcomes over the period by reducing the need for hospital admissions. Such factors may themselves influence the course of dependency and physical function at the end of life.

The very nature of this prolonged and individually varying trajectory is problematic for palliative care provision which identifies a person to be 'dying' before becoming involved. Yet there does not appear to be a clear point at which frail older people can be considered to be dying. Again, the large degree of heterogeneity within the frail older population makes identifying any degree of prognosis difficult. Also worth consideration is the impact of specific physical factors such as pain, falls, breathlessness or insomnia which may highlight where a palliative care approach could be of potential benefit rather than focusing solely on physical function or dependency. Perhaps taking a holistic approach of including psychological, social and existential or spiritual dimensions may help to highlight the impact of a potential tipping point in frailty and indicate when implementation of end-of-life care may be considered appropriate or acceptable to individuals.

It is within the non-physical dimensions for the trajectories of defined frail older people that a gap in the literature emerges. From the existing literature we may be able to highlight the negative consequences of depression (in women) and of social isolation. There appears to be a protective effect of maintaining social networks for frail older people and an interaction between caregiver burden and care practices. There are also initial descriptions which holistically integrate the different dimensions describing how older adults experience physical losses and cope with the changes that frailty brings. Such work is uniquely able to take into account the wide variation of physical trajectories.

2.5.1 Limitations of the research

Methodologically, it should be noted that the wide array of measures, and time scales of follow up may well impact upon outcomes. It also seems that measures of function may differ in terms of how much they influence the course of frailty. Furthermore, how dependencies are evaluated differs between studies allowing varying degrees of interpretation by frail individuals involved. Finally, there is potentially a wide variation between the studies in the participants investigated. This may be in their degree of initial frailty and dependence but also in the potential proportion of those

with cognitive impairment. These latter individuals are described, when analysed separately, as progressing differently from those that were cognitively intact. Therefore including them together as a single trajectory at the end of life may confuse the issue.

2.5.2 Limitations of the focused narrative review

With regard to the wide variation within the literature it is possible that this review may have missed studies that have evaluated the population over time but used different terminology or key words. Further studies may have investigated a population likely to be frail but have not used or defined the term frailty. Finally, research which is not necessarily described as looking to end-of-life or palliative care issues may actually do so but would not have been highlighted for this review.

Given the dearth of longitudinal research evidence regarding non-physical trajectories I scoped the literature for cross sectional studies of defined frail people across social, psychological and existential issues and for end-of-life holistic studies using alternative terms that may capture the experience of older people who are potentially frail.

2.6 Cross sectional studies in social and psychological dimensions

Beginning with studies looking at factors that are social and psychological Johannesen, Peterson and Avlund found the life satisfaction of 187 frail older people to be positively associated with having friends or cohabiting, maintaining a degree of self-management over one's life and continuing with usual daily activities (Johannesen, Petersen, & Avlund, 2004). Negative associations were described between receiving home care or living in a nursing home and life satisfaction while no association was found, as may be expected, with functional ability, moving home or losing a spouse. Bilotta et al studied 302 community-dwelling older adults and described those that were frail as having their quality of life negatively affected by frailty (Bilotta et al., 2010). They concluded that older outpatients living alone, as opposed to cohabiting, had greater risk of depression and increased social and

financial vulnerability although the effect was evident in those that were not frail also. The only factors that remained independently and significantly associated with frailty were depression, acute disease in the past year and dependency in basic activities of daily living. However given that 116 of the participants were considered frail and a large battery of measures were used and subject to an extensive range of statistical analysis, only tentative conclusions can be drawn.

2.6.1 Psychiatric factors

A number of studies have investigated psychiatric symptoms. A review of depression and frailty in later life, selecting both cross sectional and cohort studies of frail older adults, took a very broad inclusion criteria of frailty including studies where the term was not used but where the reviewers considered that frailty was present (Mezuk, Edwards, Lohman, Choi, & Lapane, 2012). Nevertheless, the review supports an association between depression and frailty and related states of disability and decline. Authors suggest that cohort studies point to a bidirectional link between frailty and depression as opposed to co-occurring distinct geriatric syndromes. Self-reported psychiatric illness in 5675 non demented frail older adults was found to increase with each additional frailty deficit and with the association with depression being the strongest (Andrew & Rockwood, 2007). The highest degrees of frailty were associated with a steep increase in psychiatric illness, relative to those in the lower degrees, suggesting a threshold at which the association becomes most likely. For those with the greatest frailty, psychiatric illness was reported in 35% of older people as opposed to 10% of those with more moderate frailty. Again, the authors interpret their findings with caution, due to the 'self-report' nature of the data. They do not offer evidence of causal direction, however, it is clear that the interaction of psychiatric illness and frailty is relevant to the care of frail older people.

Another study looked at health anxiety of 63 older adults with low levels of frailty and 49 with high levels of frailty in comparison with 130 non frail young adults (Bourgault-Fagnou & Hadjistavropoulos, 2009). Authors describe health anxiety as highest in the lower frailty group with no difference between the high frail and non-frail group suggesting that such anxiety is not simply attributable to age. However,

when they adjusted their scale to eliminate items that were directly related to a specific illness of an individual, such as seeking help for pain or treatment for an ailment in order to account for simply having greater health problems, the results were different showing that the high frail group and the young adults had equal health anxiety and the low frail group the least.

2.6.2 Psychological factors

Within the field of psychological factors Andrew, Fisk and Rockwood looked in detail at degrees of frailty in 5703 adults (mean age 79 years) and compared these to self-reported psychological well-being (Andrew, Fisk, & Rockwood, 2012). They found that global psychological well-being worsened with each additional frailty deficit. Worse personal well-being was also associated with increased five year mortality independent of age, gender, mental health, education or frailty level. Personal well-being sub-scales of personal growth, environmental mastery, positive relations and self-acceptance were all positively associated with frailty however purpose in life and autonomy did not show a relationship to frailty. Closer inspection of the scale used revealed that the statements used to reflect autonomy referred to personal value based statements likely to be influenced by lifelong attitudes and personality traits as the authors suggest. Purpose in life questions for example 'living one day at a time and not really thinking about the future' could also be interpreted as stable lifespan attitudes or coping strategies rather than necessarily reflecting a diminished life purpose.

Using the same scale a comparison of the personal well-being of 233 non-disabled older adults in 'warden controlled retirement housing' found that psychological wellbeing was lower in frail versus non frail older adults across all dimensions of the scale (Kirby, Coleman, & Daley, 2004). The authors also describe having a strong belief in the existence and influence of a higher power as being associated with better psychological well-being. They concluded that spirituality moderated the negative effects of frailty although their definition of spirituality was based on religious beliefs and would exclude more secular forms. It should also be noted that

participants had overall high psychological well-being scores of 83 in the frail group and 91 in the non-frail, compared to those in the Andrew and Rockwood study whose scores ranged from 20 to 78 with a mean of 44. Thus the moderating effect of spiritual belief on personal well-being of three to five points was modest and potentially of limited relevance given the relatively high psychological well-being of participants. Nevertheless, the study illustrates the potential for an interaction of spirituality on a broader sense of psychological well-being in frail older people. While causal directionality of frailty and psychological well-being remains unclear, the implications of suffering in those domains may be clinically significant in the end-of-life needs of frail older people.

2.6.3 Inter-relating dimensions

Other studies have evaluated the interplay of physical and psychological factors in frail older people. An investigation of the relationship between pain and depression described that those suffering from pain had higher rates of depressive symptoms than those who were pain free (Landi et al., 2005). Again, however, causal directionality cannot be ascertained. Saavedra and Barreto Martin looked at physical and psychological suffering and coping resources defined as elements that induce a sensation of well-being (Saavedra & Barreto Martin, 2008). They described relationships between perceptions of time passing, well-being and of personal interpretations of a situation to be more salient to suffering than the situation itself. However, statistical generalizations are perhaps hard to draw given the small sample size of 40 participants and the large battery of elements assessed. What they do highlight clearly is the wide variation, from person to person, in the range of symptoms as well as the varying degree of worry that these brought. They also described a general lack of fear or anxiety about death.

Finally Li et al describe how having a strong self-efficacy belief, that is a person's belief that they can perform an intended behaviour (Bandura, 1986), or living with a spouse can protect older people against further decline in ADL function (Li, 2005b). What these results highlight is the interrelatedness of different dimensions.

There remain some studies worth mentioning that do not define or offer the term frailty at all yet can illuminate the importance of the different dimensions of need in interaction with each other for older people. One study that investigated the social experience of end-of-life looked at the care experience of 120 deceased low income older people (Kramer, Boelk, & Auer, 2006) via retrospective reports of family conflict from nurses and social workers. This study did not address change over time; however it does offer a retrospective understanding of how a social situation could impact upon the end-of-life experience. Authors concluded that family conflict, occurring between individuals within the family or between family and those involved in health or social care provision, was present in over half of the cases. Such conflict was described as causing increased stress for the older person, to have led to their wishes and care being compromised and in delaying or restricting the implementation of care plans. Although a degree of caution should be taken with these findings, given that they are proxy and retrospective from social workers, it is nevertheless an interesting view of an aspect of the social difficulties perhaps faced when older people progress towards death.

Interesting interactions between psychological and physical domains were described in an investigation of 'time referent' life satisfaction of 164 people with a mean age of 91 (Palgi & Shmotkin, 2010). Participants rated their life satisfaction in the past, present and future and were found to show four clear trajectories which were then plotted against adaptation markers of depressive symptoms, self-rated health, physical performance and every day activities. The most adaptive trajectory, a stable pattern where 'past satisfaction equals present and future satisfaction and these equal or exceed the middle point of the rating scale' was shown by 21% of the sample. The least adaptive, the unreported trajectory, where no evaluation of satisfaction is given for any of the time referents was found in 37% of participants. The authors hypothesized that this group of older people represented 'those who are mentally exhausted with a pronounced failure to produce an appraisal of their life satisfaction within a time perspective frame' (Palgi & Shmotkin, 2010: 584). Although the causal direction of this finding is not clear it may be illustrative of how focusing on biological or medical markers for imminent decline to death may miss important

triggers to end-of-life care from other domains. Perhaps it is at this stage of ‘mental exhaustion’ that frail older adults may benefit from a palliative care approach. The concept of mental exhaustion, however, is not new and has been described by Lawton in her study of hospice patients yet may be present for a protracted period in frail older people in the community (Lawton, 2002).

2.6.4 Holistic studies

Given the value of the holistic qualitative approach adopted by Nicholson (Nicholson et al., 2012) in its ability to account for individual variation as well as inform how different dimensions may interact, I now report on similar research that has looked at older adults who are not defined as frail but may be a potentially similar population. Two studies conducted by Liz Lloyd provide very valuable analyses particularly regarding interactions between different dimensions (Lloyd & Cameron, 2005; Lloyd, 2011; Lloyd, Calnan, Cameron, Seymour, & Smith, 2014). The first collected qualitative and quantitative data with adults aged over 80 over one year. Issues highlighted related to attempts to maintain control over one’s life and experiencing health and mobility changes. Mental health difficulties were associated with physical restrictions, compromising the ability to leave the house as desired, while socio-economic difficulties influenced how life changes were experienced. Older adults also gave accounts of death and dying in different ways. These involved focusing on making legal and financial preparations, wishes to determine their own death and fears of burdening others or not engaging in future contemplations either by adopting a stoical stance or by taking a religious or spiritual view. The second study involved repeated interviews over 18 months with 34 adults aged 70 years and over with ‘health problems that had generated varying degrees of need and support and care’ (Lloyd et al., 2014: p6). The older people talked of maintaining supportive networks of family and friends, and how these networks influenced their future care decisions. Participants also discussed existential issues in their struggles to live with a precarious existence. Despite finding the end-of-life difficult to discuss they described varying levels of having made their preferences clear and of having made plans accordingly. Importantly, some had made no such plans because they felt they

had no control over the future. Older people's accounts revealed challenges to maintaining dignity in receiving health and social care. Lloyd points to interactions of physical and psychological difficulties in how the participants' understanding of self was challenged in the face of their changing circumstances, and their attempts to cope and adapt. Maintaining independence and accepting help was highlighted as a difficult balance to strike as loss of independence was associated with fears of burdening others and was similarly described in a cross sectional qualitative study of older people (Lloyd-Williams et al., 2007).

Using formal definitions of frailty is, perhaps understandably, controversial within the social sciences. Grenier describes an active resistance to the label of frail in older women and that such an identity is foisted upon them by others (Grenier, 2007). Gilleard et al cite the need for narratives to create identity claiming that frailty is what is left over after identities of disability, chronic illness and the functional third age are removed (Gilleard & Higgs, 2011). Many resist the reductive notion of labelling individuals and indeed qualitative studies, being the ones more likely to perhaps investigate non-physical dimensions, may take an approach that is less comfortable with such 'syndrome' labelling. Finally, studies may involve frail participants but without reference to nearing the end of life so may be less transferable as palliative care evidence.

2.7 Conclusions

There is research that describes possible end-of-life physical trajectories for frail older people; however there is a paucity of research extending into social, psychological and existential or spiritual domains. There is a need for longitudinal research that can offer an understanding of the end-of-life experiences across different dimensions of need over time for frail individuals. Research that can illuminate how different dimensions may change and interact would be useful in eliciting the needs of frail older people. Perhaps indicators for end-of-life care within non-physical domains could emerge and offer a way forward for palliative care interventions rather than focusing on physical triggers. It may also be useful to

look separately for those with and without cognitive impairment as their inclusion together may confuse outcomes.

Across all of the dimensions, much of the difficulty in understanding trajectories at the end of life resides in the methods utilized and terms used to describe the population. Methodologically, studies may be longitudinal yet do not describe change over time but rather attempt to describe causal connections especially when it comes to non-physical domains. There is also huge heterogeneity in how frailty is defined and how the term is actually used. Although there are clear arguments against labelling people as frail, without some measure of agreed understanding of a frail population it may be difficult to tailor care to the needs of older people at the end of life who have not been identified to be dying from a specific disease.

There is a clear gap in the literature investigating the experiences of frail older adults from their own perspective. Qualitative longitudinal research could help to fill this gap and is needed in order to understand holistic and dynamic palliative care needs. Such methods may also offer a unique opportunity to account for the individual variations in physical trajectories and allow a holistic integration of different dimensions of need as they change over time. How such inter-relations occur may offer a valuable way of understanding the complexity of palliative care needs of frail older people.

The approach used to review the literature, focusing on multidimensional change surrounding frailty towards the end of life, was undertaken to inform the model being considered. However, this approach may then have given less detailed attention to other ways of investigating frailty towards the end of life. Studies such as those of Lloyd (Lloyd & Cameron, 2005; Lloyd, 2011; Lloyd et al., 2014) and Nicholson (Nicholson et al., 2012) ultimately proved highly illuminating and relevant in terms of trying to understand the experiences of frailty. The particular focus of the review also missed investigating experiences of other conditions or illness, however these are considered later in the thesis in integrating theories of biography and illness.

2.8 Summarizing the review

In summary, emerging from the literature are two main factors. Firstly, is the lack of research looking specifically and holistically at the experience and needs of frail older adults; secondly are attempts to engage with older persons in care planning to anticipate their likely needs, a key element of the palliative care approach. There is a need for patient centred research because of individual variation in physical trajectories. The utility, then, of a contextually situated, patient-centred prospective longitudinal study to investigate the experiences, needs and preferences of frail older people as they happen and change over time is clear.

2.9 Next steps

A qualitative (QL) research method would seem most advisable for looking at the experiences and needs of frail older people. As argued by Kearney et al, not enough in-depth qualitative research has been carried out into the perspectives of older people, amongst others (Kearney, Worth, Paterson, & Kendall, 2003). QLR methods have become recognised as important in medical research due to their ability to investigate complex, contextually based phenomena. The Lancet has highlighted that qualitative inquiry has been described as offering a broader understanding of the social and illness experience of individuals within their natural context (Malterud, 2001). In contrast, quantitative work requires a degree of decontextualisation and reduction of variables and so may struggle to grasp the complex nature of the illness experience. This would seem especially important given the complexity of frailty.

Most qualitative medical research, however, has remained cross sectional telling us only about experiences at a given time point. A longitudinal qualitative approach (QLLR) offers the potential to gain an understanding of how experiences evolve or change across time. Research within the social sciences, for example in anthropology (Smith & McVie, 2003), education (White & Arzi, 2005), psychology (Brown & Gilligan, 1993; Mauthner N & Doucet A, 1998) and social policy (Corden A & Millar J, 2007a; Corden A & Millar J, 2007b) have found a QLLR approach to be a useful research method for capturing personal experiences as they change across

time. While the approach is being developed in the social sciences (Holland J, Thomson R, & Henderson S, 2006; Thomson & Holland, 2003), it has received little practice or attention within medicine. As the progression of frailty, illness and dying occur as processes and needs change, a prospective QLLR method may be useful for eliciting the changing experiences and care needs of people at the end of life. The method has been used to describe the end of life in cancer and organ failure (Murray & Sheikh, 2006) yet has received little attention in those that are frail.

That a qualitative approach may be more accepted than a quantitative approach by frail older people themselves was reflected on by Kirby, Coleman and Daily following their questionnaire based study ‘many participants did not like having to categorize their answers and did not like giving a generalized response, particularly when they felt that their response might vary from day to day.’ (Kirby et al., 2004: p128). They further elaborated that ‘Many preferred to explain their situation, providing a context and justification for their chosen answers. It may be more appropriate for researchers working with this population to explore the use of formats that are more qualitative’ (Kirby et al., 2004: p128).

Accordingly, in this study I aimed to elicit the experiences of frail older people in order to inform the development of patient centred, needs based models of care. As new more patient centred research methods may be required in order to meet this end, in the course of this study I reflect upon using a longitudinal qualitative approach. The following chapters take this forward by beginning with an explanation of how frailty was defined for the purpose of the current study then by outlining the theoretical underpinnings of the research and rationale for the methods chosen.

Chapter 3: Methodology

3.1 Introduction

In the previous chapter I described the rationale for holistic, patient centred research for investigating the end-of-life experiences of frail older adults, in order to understand their multidimensional needs and experiences as they change over time. In this chapter I will explain why a qualitative, longitudinal (multi-perspective) approach is suited to achieving this goal, describe how I went about carrying out such a study and offer justifications for the methods used. First, I will give the overall aims of the study and outline its theoretical underpinnings. Second, I will describe the ontology, epistemology and theoretical perspective and follow by explaining the methodology and design. Third, I will describe the methods of recruitment, data generation and analysis, the reflexive approach taken and discuss how ethical issues were handled.

3.2 Aims

This study aims to understand the changing needs and experiences of frail older adults towards the end of life and to reflect upon the utility of a qualitative longitudinal (multi-perspective) research method for the group.

3.2.1 Research Questions

1. What do frail older adults describe as their needs and experiences over time towards the end of life?
2. How does physical, social, psychological and existential well-being change over time?
3. What are the benefits and constraints of using a qualitative, longitudinal method with this group?

3.2.2 Theoretical Framework

When describing the research methods used to generate and analyse data it is important to also explain the underlying assumptions about knowledge and meaning.

This is particularly important in order to make sense of the findings, and any claims or inferences made about them. In the following section I explain the theoretical stance taken for the study.

3.2.3 Ontology and Epistemology

Crotty states that ‘writers in the research literature frequently have trouble keeping ontology and epistemology conceptually apart’ and focuses discussion from an epistemological starting point (Crotty, 1998: 10). However, at the most basic level ontology is concerned with what exists. There are two main ontological perspectives which are commonly discussed. The first are realist ontologies, which do not question the fixed existence of ‘things’ or ‘facts’ in the world and form the underlying assumptions of quantitative research methods. Such methods focus on measurement and probability to test a null hypothesis. They require the exclusion of confounding variables and, as such, remove much of the context surrounding the issue being explored. However, how someone experiences illness, or functional decline, will be entwined with the broader context of their lives and not easily quantifiable. The second are relativist ontologies, which regard facts as fluid and elusive, with multiple realities. This forms the underlying assumptions of qualitative research. (Denzin & Lincoln, 2000). Qualitative research methods can take account of the wider context within which knowledge is understood and may be better placed to explore the accounts of individual experience. The terrain between realism and relativism as necessarily distinct is, however, contested. Numerous theorists have proposed versions of realism such as subtle realism (Hammersley, 2002) or critical realism (Banfield, 2004) that attempt to bridge the gap between relativism and realism. Hammersley argues that since relativism is subject to a circularity of argument where knowledge becomes true only in relation to a particular framework or culture, what value can it have (Hammersley, 1992)? Subtle realism considers knowledge as socially constructed and based on assumption while rejecting the notion of independent and knowable phenomena. Hammersley argues that research should depend on context and purpose while remaining vague, as Banfield claims (Banfield, 2004), about what can be taken as context and purpose. Banfield has criticised Hammersley’s argument as inadequate for addressing the theoretical

problems of social research by favouring epistemology while avoiding ontology (Banfield, 2004). He states that subtle realism falls into the 'ontic fallacy where 'what is known' is reduced 'to what is' (Banfield, 2004: p61) and the 'epistemic fallacy where 'what is' collapses into 'what is known' and advocates a critical realist stance (Banfield, 2004: p61). Critical realism holds a realist ontology that accepts that an independent reality exists while at the same time holding a relativist epistemology that recognises our capacity to observe and understand reality remains socially constructed and essentially fallible.

Epistemology refers to beliefs about knowledge (such as "what can be known"). As such, the theory of knowledge will relate to what we can know about the world, the 'things' in it, and from where our knowledge derives. Crotty described three main epistemological perspectives of objectivism, subjectivism and constructionism and I will outline each in turn (Crotty, 1998). An objective epistemology describes absolute truth or reality that can be discovered, and knowledge as therefore objective and neutral. Reality comes from the object (Crotty, 1998). A subjective epistemology assumes that nothing has inherent meaning. Reality and meaning comes from the subject, that is, the person perceiving it. Constructionism, describes the reality that we perceive as constructed by our social, historical, and individual contexts. In this way, there can be no absolute shared truth because meaning and understanding does not occur in isolation from the world around us and is inherently social. Individuals are described as constructing realities for themselves within their social interactions and personal and cultural history (Crotty, 1998). That is, reality does not come from the subject or the object, but understanding and meanings are constructed from interactions between subject and object (Crotty, 1998). The epistemological approach taken influences how data is generated, how it is interpreted and the resulting claims that can be made (Denzin & Lincoln, 2000).

In recent years the social sciences have been described as moving towards a constructionist approach, with many social scientists now describing the role of language as a primary vehicle for making sense of our experiences (Murray, 2004). Crossley explains that we understand ourselves through the medium of language, in

writing and talking, but also that individuals are constantly engaged in the process of constructing ourselves, and our sense of meaning through such processes (Crossley, 2000). Specifically, critical health psychology has questioned positivist based assumptions of a traditional psychological approach to understanding illness experiences, and promotes the utility of a constructionist, contextualised, qualitative approach (Murray, 2004; Crossley, 2000; Murray & Chamberlain, 1999). It is argued that our understanding of health and illness will remain vague if isolated from the cultural or social context in which they occur. It is in relation to these contexts that we make sense of and interpret our experiences (Crossley 2000).

Accordingly, frail older people exist within their own personal and cultural history, constructing their own meaning and understanding of their experiences in relation to, and in interaction with, their social and cultural environment. Similarly, my background as a nurse with an academic background in psychology, may influence the perspective that I take as a researcher (Carter & Little, 2007). Psychology as a discipline is invested in both realist and relativist paradigms. However, my health psychology training emphasised a critical stance, and reinforced the values instilled in me during my nursing training and practice of the importance of listening to and engaging with people and the value of their subjective viewpoints. Thus my understanding of the research interviews was constructed with regard to the wider social, cultural and historical context of the interviewee and of myself. This current research can be described as utilising a constructionist epistemology within relativist ontology. It could be argued that a reality exists that I have tried to understand, yet how this could be disentangled from the social element of the interview or what claims to truth could then result would remain open to question.

3.2.4 Theoretical perspective

In terms of the theoretical perspectives, constructionist approaches to research include interpretive methods such as phenomenology and hermeneutics. Phenomenology focuses on how individuals make sense of the world, and emphasises explanations over interpretations. However, hermeneutics, differs from

phenomenology by deriving empirically based interpretations of data carried out with explicit recognition of the cultural and historical context (Crotty, 1998). Here, the researcher is not making any attempt to 'set aside' preconceptions, in the manner that Husserl advocated (McConnell-Henry, Chapman, & Francis, 2009), but is reflexive about their impact upon the interpretations made. A hermeneutic approach, taking Heideggarian principles (McConnell-Henry et al., 2009), explicitly acknowledges the subjectivity of the reader in influencing how understanding is arrived at and interpretations made. The circularity of this process is described as follows: 'understanding turns out to be a development of what is already understood, with the more developed understanding returning to illuminate and enlarge one's starting point' (Crotty, 1998: 92). The second aspect of this 'hermeneutic circle' stresses that the meaning of text must be found within its context. In fact, hermeneutics has been described as essentially involving cultivating the ability to understand things from somebody else's point of view, but also to appreciate the cultural and social forces that may have influenced their outlook (Crotty, 1998). The central principle here is that it is only possible to grasp the meaning of an action or statement by relating it to the whole discourse or world-view from which it originates.

Hermeneutics crosses disciplines, notably to literary criticism and reading theory, which questions the place or status of the author, the text, or the reader in interpretation. Here the place of the reader in interpreting and interacting with any text is explicit and reflected upon, and can be seen as taking empathic, interactional or transactional modes (Crotty, 1998). I set out to use all three approaches in analysing data. I began with the empathic, where the reader is open and receptive, and attempts to view the text from the perspective of the author. I moved on to the interactive approach, where the reader is regarded as conversing with the author and engaging with what the author has to say and taking a more critical stance. Finally I used the transactional mode, which looks to engage with the text to produce or interpret something new that is not explicitly in the text. Such explicit emphasis on context ties usefully to the constructionist epistemology and the discursive and contextualised turns in the social sciences.

3.2.5 Methodology

Within qualitative research there is a grand array of methodological approaches that can be adopted to gather and analyse data. These range from the detailed linguistic approach of discourse analysis, to observational ethnographic techniques. Choosing a particular approach must resonate with the theoretical underpinnings, and overall aims of the research. A narrative methodology would allow frail older people to make sense of and give voice to their experiences and needs as they change over time and is explored below.

3.2.6 Narrative enquiry

Within a constructionist, interpretive, hermeneutic framework, one form of investigation is the narrative approach. Narratives do seem particularly pertinent to the theoretical stance taken so far, as they are described as: organising our experience of time and constructing meaning (Murray & Chamberlain, 1999); being inherently social (Elliott, 2005) and as developing out of a particular context for a certain audience (Smith & Sparkes, 2005). Additionally, narratives encompass the temporal element of a longitudinal design as they are also described as essentially chronological (Elliott, 2005). Applying a narrative approach to studying the experiences of illness and death has gained academic interest in recent years. This was prompted by the 'illness narratives emerging in the public domain' (Bingley et al., 2006), and as illness experiences appear to be readily expressed in narrative form (Elliott, 2005). Disciplines such as medicine and psychology are beginning to employ narrative as a useful method for researching health and illness. Some have researched the storied nature of traumatic illness experiences and HIV (Crossley, 1999), the experience of cancer (Frank, 1997) or the palliative care needs of those with lung cancer and heart disease (Murray et al., 2002). Others have found that a narrative form is often taken to express the impact of chronic illness on a person's sense of identity (Charmaz, 1983).

Although there is no current consensus on the definition of narratives, or their key features, Elliott described narratives as temporal, meaningful and social (Elliott,

2005). Firstly, the temporal element relates to sequences of events, in their chronological sense, but also to their more detailed causal or linked sense. In this respect my research, which is looking longitudinally at changes in the experiences and needs of frail older people, relates well to this element, but also to individuals' understandings of living with frailty. Secondly, from the aspect of meaning making, illness stories have begun to proliferate in the media, as well as in the research arena in recent years, in part because of the biographical nature that individuals' understanding of health and illness generally takes (Bingley et al., 2006; Crossley, 2003; Murray et al., 2002). Arthur Frank describes how ill people often respond with stories when asked about their medical history (Frank, 1997). People have a need to make sense of events, especially those that are adverse, and becoming frail is unlikely to be any exception. This study investigates how participants attempt to build their frailty into the fabric of their own story. Furthermore, the element of meaning making relates to the important patient-centred angle of my research in that it allows participants to determine what areas are most important or salient to them. Thirdly, narratives are described as inherently social in that they are produced for a specific audience and with a specific listener. We cannot disentangle the listener from the process of story production. Elliot describes collaboration, where the listener allows the story teller to know that their justifications have been understood (Elliott, 2005). Cornwell describes public narratives, which are more socially image managed accounts versus private narratives as would be told to close friends (Cornwell, 1984). Carrying out repeated interviews involves a relationship being built up between myself and the participants. This will alter the type, and manner of disclosures offered, facilitating the production of private accounts as participants become more familiar and trusting of both myself and the interview process. Stories are produced by individuals with regard to their audience, but I would also posit a missing, fourth psychological element - that they are also created intra-personally. As people are making sense of their experiences through the stories that they tell, the justifications that they offer, the explanations that they give, so also they are making sense to themselves. We are all attuned to our idealised and actual selves, that is, who we think we are and how we would like to be. Part of our 'actual

self”, in our own view, stems from attempts to mould circumstances that cast us in less negative lights in order to maintain our self-esteem.

Narrative researchers have engaged in debate about the foundations of their research, notable in the criticisms offered by Atkinson of the approaches of Frank, Mishler and Kleinman (Atkinson, 1997). This will be explained further in an outline of the overall criticisms in chapter 8.

In summary, this research, aimed at understanding the experiences and needs of frail older people towards the end of life, will be applying a narrative approach, informed by an interpretive, hermeneutic theoretical stance.

3.3 Reflexivity in qualitative research

Reflexivity is considered fundamental to qualitative research. Reflecting on our emotional, intellectual and social positions in qualitative research can help to ensure rigour; that is trustworthiness, accountability and transparency (Finlay, 2002; Mauthner & Doucet, 2003). Finlay describes variants of reflexivity, including introspection, intersubjective reflection and mutual collaboration (Finlay, 2002). For the purpose of the current research, reflexivity has involved a degree of introspection, whereby my own experiences and background are acknowledged, and their impact reflected upon. Intersubjective reflection was used to recognise the situated and negotiated nature of the research encounter, where ‘mutual meanings emerge within the research relationship’ (Finlay, 2002: 215). With mutual collaboration, I expected the participants to naturally undertake a degree of self-reflection during interviews, but also in the interim periods between them. As such, I cultivated my awareness of the reflections that participants brought to the encounter, and utilised those as well as my own, to collaborate in the production of topics discussed and in the analysis.

3.3.1 Reflexivity in data generation

The process of reflexivity is also central to qualitative interviews, which can be considered as co-constructed between the researcher and the researched (Mishler, 1986). Crucial to the premise of the reflexive researcher is to acknowledge that I am not a passive recipient of people's words. I come with my own history, background, culture and biases and I tried to remain as open to these as possible and to see that I am, in fact, an active participant in the process from the first meeting to each interview and telephone conversation. The co-constructed accounts that I gained were influenced by a number of factors. Firstly, how I presented myself both consciously and subconsciously (a researcher, a psychologist, a nurse, an educated middle class female). Secondly, how I understood the participants (as frail older adults, as having lived through a particular time in history, as having specific illness and specific needs, their own home and social circumstances) and thirdly by each participant's need to present a particular aspect of themselves in light of how they perceived me and our interactions. Certainly, there were times during the interviews where one or another of these roles appeared to dominate in either my mind, or that of the interviewee. Additionally, as I had recruited the participants from a National Health Service (NHS) day hospital this would have undoubtedly influenced how they regarded me and associated me with health care services and the subsequent accounts that they gave me.

However, reflexivity cannot simply be reduced to being aware of my own influence on the interviews but also at other times. I tried to be aware of how I thought and felt before during and after the interviews and documented in my field notes accordingly. A technique that I planned across all interviews with the older adults themselves was to document in my field notes the dominant emotion that I felt on leaving a meeting.

3.3.2 Reflexivity in analysis

During the analytical stage I attempted to remain open about my motivations and biases and how they may affect data interpretation. I felt it was important for me to continue to acknowledge points where my own background was influencing my evaluations. The chosen method of analysis, the Voice Centred Relational method (VCRM) devised by Brown and Gilligan provides an instrument for reflexive data analysis as it comprises a built in reflexive component (Brown LM & Gilligan C, 1992). This will be explained further in section 4:11:2. I also aimed to take account of, and build in to the analysis, the political, cultural and historically situated nature of the interviews. This was instrumental to the analytical method chosen, as well as the ongoing relationship between myself and the participants.

3.3.3 Reflexivity in evaluating the method

The research process and outcomes themselves were also evaluated in a reflexive manner. Finlay states that reflexivity can be a valuable tool for evaluating the research process, methods and outcomes (Finlay, 2003: 16). I have reflected upon how the on-going relationship develops in the repeat interview design, how this may have shaped research findings and on any added value of the repeat (multi-perspective) interviews, in order to ascertain the potential benefits and constraints of the qualitative longitudinal (multi-perspective) method. Such a reflexive method of evaluating the research methodology has been chosen as this relates to the overall theoretical positioning of the research by focusing on how outcomes are constructed, and on their contextual and fluid nature, rather than looking for steady, directly transferable outcomes.

3.4 Study design

3.4.1 Qualitative longitudinal research

Qualitative research offers the ability to investigate complex, contextually based phenomena. However, most qualitative medical research has remained cross sectional, telling us only about experiences at a given time point. A longitudinal

qualitative approach (QLLR) offers the potential to gain an understanding of how experiences evolve or change across time (Smith & Firth, 2011). The QLLR method has a history of use within social science and is described as experiencing a resurgence of interest resulting from an interest in process, change and the individual (Thomson, 2007). QLLR is described as useful for studies investigating the experience of process, transitions, pathways, changes and adaptation (Neale, Henwood, & Holland, 2012; Holland J et al., 2006). It is however only beginning to be used in medical research (Murray et al., 2009). Recently, studies carried out by colleagues in the Primary Palliative Care Research Group at the University of Edinburgh have utilized the approach for investigating the end-of-life experience of people with lung cancer and heart disease (Murray et al., 2007), glioma (Cavers et al., 2012), COPD (Pinnock et al., 2011) and colo-rectal cancer (Carduff, 2012). Benefits generally relate to being able to access temporal elements of the end-of-life process and in gaining access to sensitive issues and more private, as opposed to public, accounts of people's lives at this stage.

QLLR is not a single method for data collection and analysis but can be carried out in many different ways. These include life history, biography, diaries, scrapbooks, or observational studies. However repeated qualitative interviewing is the method most often used in health service research. QLLR views time as multidimensional, and researchers investigate how individuals move through time and make sense of their lives in relation to it (Neale & Flowerdew, 2003). Therefore, QLLR must be more than collecting data at repeated cross sections and simply comparing between time points. QLLR focuses on change, and process, across the whole time period of the research, with the researcher building iteratively over the period. Ensuring that the same researcher follows the same participants, allows a relationship to be built during and between interviews. It is this ongoing and deepening relationship that can gain access to sensitive issues and more private accounts.

Finally, participants themselves also undertake more than a set of discrete interviews as they can engage in an in-depth process of self-reflection during the interim periods with the resulting increased awareness (Corden & Millar, 2007b).

With respect to appropriate timescales for qualitative longitudinal research Saldana describes the need for a very long time period in order to adequately capture change (Saldana J, 2003), however this is debated by others who advocate that timescales be dictated by the phenomena under investigation (Neale et al., 2012; Murray et al., 2009; Corden & Millar, 2007b).

3.4.1.1 A Case Study approach

Case studies, following an individual over time, allow an understanding of how and why change can happen as it does (Thomson, 2007), and the opportunity to investigate the inter-connections between changes (Smith & Firth, 2011). As such, they offer the unique opportunity to evaluate how different dimensions of need can inter-relate and change over time, making it an ideal approach for the current study.

However QLLR has unique challenges. The constraints of QLLR, relating to the sheer volume of data involved have been well documented (Thomson, 2007; Murray et al., 2009; Smith & Firth, 2011), however strategies can be employed that can impose structure and form on the method. Smith describes focusing data collection by viewing first interviews as exploratory then building iteratively to inform follow up interviews (Smith & Firth, 2011). In managing the data sets of QLLR, Thomson explains that traditional methods for managing qualitative data, such as framework analysis (Ritchie & Lewis, 2003) or computer software packages, can be overwhelmed by the volume of data (Thomson, 2007). Thomson describes the need for novel strategies such as employing timelines (Saldana J, 2003) while Smith and Firth advocate a framework for specifically profiling the case at time-point one and then tracking change (Smith & Firth, 2011). How I managed the data set for this PhD, informed by these discussions is described in section 4.10.4.1.

3.4.1.2 Flexible timing of interviews

As Corden and Millar describe, qualitative longitudinal research generally employs pre-determined intervals between interviews, according to the research agenda (Corden & Millar, 2007b). In this study I have adopted a flexible approach in order to schedule interviews at times that may best capture change. Accordingly, I planned

to make telephone contact with the participants every two months and to schedule follow up interviews at times to capture changes in any of the dimensions of need, physical, social, psychological or existential.

3.4.1.3 Qualitative multi-perspective research

Qualitative methods of data collection often focus on single individuals. Valuable insights are gained in this way; however few experiences occur in a vacuum: especially those that are health or illness related. In looking at the experiences and needs of people approaching the end of life, those in supportive roles, experiencing and living with the person's situation can offer additional insights and perspectives. The scope may be widened further to include those who have regular involvement with the individual in a professional capacity.

Multiple perspectives can enhance the understanding of the individual's situation, of their relationships, or their interactions with each other. They can highlight roles or identities of participants within their families, their communities or their professions, and how these can be maintained within such multifaceted and unique relationships. Furthermore, actually involving the informal carer in the research can help to alleviate anxiety about the involvement of their relative or friend in the research. These additional accounts can explore complex, complementary, as well as contradictory perspectives and offer richer insights than the single perspective (Murray et al., 2009; Murray et al., 2002; Clayton, Butow, & Tattersall, 2005). Finally, including informal carers in end-of-life research can facilitate proxy accounts surrounding the circumstances of death. Multi-perspective interviewing does come with constraints, specifically in maintaining confidentiality, and during joint interviews. This will be discussed in more detail in sections 4.5.3 and 4.8.5 respectively.

3.4.1.4 Qualitative multi-perspective longitudinal research

Combining longitudinal and multi-perspective methods should offer a uniquely detailed insight into the experiences and needs as understood by frail older people and those most involved with them, not only through the method itself but through

the developing relationship between the researcher and the participants during the course of the study. Murray et al have found an integrated longitudinal and multi-perspective research method to be beneficial for understanding the changing experiences for people with lung cancer and heart disease (Murray et al., 2007). As this PhD aimed to understand the multidimensional and changing needs and experiences of frail older people a qualitative, longitudinal, multi-perspective approach was taken.

3.5 Professional Ethics

3.5.1 Ethical Review

Ethical approval for this research was gained from the Lothian Research Ethics Committee (LREC) in January 2009. This process helped to clarify and engage with the fine details and eventualities of the actual process of carrying out the study. Research and Development approval and honorary NHS contract was granted by the local NHS board. Details of these can be found in the appendices (Appendix 3).

3.5.2 Data Handling

The data for the study comprised background demographic and personal details, consent forms, audio recorded interviews, transcripts and field notes. As required by LREC all data were handled sensitively and confidentially. All paperwork was stored in a locked cabinet in the university and all electronic data stored securely in a password protected system that only I had access to. Audio-recordings were deleted from the portable device at the earliest opportunity. Only myself, and my three supervisors had access to the study data, however names and addresses of participants were known only to me.

3.5.3 Maintaining confidentiality

3.5.3.1 Anonymity and naming

From the moment that an older person agreed to participate in the study they were allocated a number. Any linked informal carer or professional was allocated the

number with ‘carer’ or ‘professional’ added in order to maintain the cases together. I was left with the option of then reporting the research using numbers or pseudonyms, each with potential pros and cons (Guenther, 2009). Given that I aimed to convey the experiences and needs of frail older people, from their own perspective I felt that using a number to do this would make it harder to hear the actual voice of the participant coming through. Guenther has suggested that using a name or a pseudonym can achieve the goal of giving voice to participants and subsequently improve the cohesive quality of the research (Guenther, 2009) . However, I was cautious when I applied the pseudonyms to ensure that participants were as unrecognisable as possible. Pseudonyms did not sound similar and had different initials to the real participants’ names. Further anonymity was ensured in the accounts told to me by participants. Any other identifying features such as names of institutions, geographical areas or family members or friends were also changed. I do recognise that such measures would ensure that participants would be unidentifiable to most, but may still be recognisable to close family members or friends. Using a strategy described by Nicholson I have aimed to ensure that my analyses are presented as my interpretations rather than a participant’s fixed reality and to ‘situate confidentiality within a wider ethical framework’ by being mindful of the tone of what I present (Nicholson, 2009a: p82).

3.5.3.2 Confidentiality within multi-perspective research

Issues of confidentiality are present in all research but can be exaggerated in multi-perspective studies. When I spoke with older people and informal carers separately, I had to be mindful that I did not introduce a viewpoint or experience raised by the other person, unless brought up by the person being currently interviewed. The same applied, perhaps more importantly, to professionals. I ensured all participants that what they told me would not be revealed to other linked participants. This was necessary when individuals were at odds with each other or each other’s accounts. This was a considerable undertaking and was at times difficult, but was aided by focusing on listening and guiding an interview and by building on cues during the interview. However, I do have to acknowledge that there may have been times where

my body language or my reaction, explicit or implicit may have made it clear during an interview that I had, or had not heard a particular viewpoint before.

3.6 Participation

3.6.1 Sample size

Qualitative research generally is concerned with the meaning rather than the generalizability of findings (Crouch & McKenzie, 2006). Such studies are not aiming to recruit sufficient numbers of participants in order to maximise statistical power. That said, explicit suggestions for adequate sample size in qualitative methods are hard to find. Indeed Creswell describes that narrative research can be limited to as little as one or two individuals, while grounded theory studies can involve upwards of 30 individuals (Creswell, 2012: p126). Arguments can instead rest on the concept of theoretical saturation within the data (Mason, 2010). It is my view that with the narrative approach for the current study and its iterative and evolving hermeneutic stance, that theoretical saturation may never be reached. Instead I chose to focus on achieving depth of description, as argued by Crouch and McKenzie 'For depth to be achieved, it is much more important for the research to be intensive, and thus persuasive at the conceptual level, rather than aim to be extensive with intent to be convincing, at least in part, through enumeration' (Crouch & McKenzie, 2006: p494). I therefore aimed for a sample size which was guided by the aims and objectives of the study, and by practicality in accounting for the labour intensiveness of qualitative research and longitudinal research generally. This PhD was aiming to look in great detail at single individuals over repeated interviews and at multiple perspectives. Each central participant could generate up to seven interviews allowing for the possibility of three separate interviews with participants and carers and a professional carer interview, there was a potential data set of 84 interviews. In consultation with the research team I considered that recruiting 12 individuals would allow me to build up relationships with the participants, be sufficient to meet the aims and questions of the research, and to generate rich, in depth and pragmatically manageable data.

3.6.2 Plan for managing attrition

There was the potential that participants may be unable to participate beyond the initial interview due to death, cognitive decline or simply no longer wishing to participate. Therefore, it was planned that if only one interview had taken place with a frail older person that further participants would be recruited to maintain the sample of 12 individuals studied over time.

3.6.3 Setting

Participants were recruited from a day hospital in Scotland that caters for older adults referred to the service by general practitioners when it is felt that they need a medical review, are having falls, or are generally declining yet do not require admission to hospital. The facility offers weekly, or twice weekly, full day sessions where individuals are brought by ambulance in the morning and spend the day participating in assessment and therapy sessions with physiotherapists and occupation therapists, as well as monitoring and assessment of their medical needs with nursing and medical staff. The days include lunch and opportunities for social interaction between sessions with professionals. The decision to recruit participants from an out-patient, as opposed to acute hospital setting, was taken in order to maintain the focus on day to day life rather than that of a post-hospitalised experience. Participants would inevitably experience periods of hospitalisation, but this would remain within the context, for them as well as for me, of their day to day experiences.

3.6.4 Sampling

The sampling process in this study did not aim for statistical generalizability, or to look for general tendencies of a larger group, rather to reflect the variability of frail older adults and thus generate a range of case stories, whose experiences would resonate with those of many in the larger population. As such, I chose a purposive sampling approach which “allows the researcher to choose a case because it illustrates the feature in which we are interested” (Silverman, 2000: p104). The sample aimed to approximate the demographics of those over the age of 75 in terms

of gender balance (ONS, 2006), as well as a balance of those that lived alone and those that co-habited with another person.

3.6.5 Prognosticating

As this study aimed to investigate needs and experiences towards the end of life, some level of prognostication was required when recruiting participants. Prognostication is notoriously difficult for frail older people, in terms of predicted survival and such evaluations tend to be extremely complex to carry out. I needed a pragmatic tool that would relate to clinical practice and yet could attempt to identify frail older participants that were nearing the end of life during the course of the study. The Clinical Frailty Scale (CFS) tested by Rockwood et al (2005) found that frail older people who were considered moderately or severely frail according to the clinical frailty scale had an estimated mortality of 30% after 20 months (Rockwood et al., 2005). Additionally, it was found to correlate well in this respect with other more complex measures. In order to identify those approaching the end of life I decided to recruit older people that could be classified as moderately or severely frail according to the CFS (see appendix 12)

3.6.6 Recruitment criteria

Participants over the age of 75 were selected as previous research details that 66% of all deaths now occur after this age (Office for National Statistics, 2008), offering the potential to interview individuals as they approach the end of life. Selecting an older age group, would potentially reduce the likelihood of selecting participants from a broad social economic status range.

3.6.6.1 Frailty

The definition of frailty proposed for the research refers to those definable as both bio-medically vulnerable and psychosocially dependent, according to those involved in providing care for these individuals. An explanation and justification for the particular approach used for defining frailty in this study was outlined in chapter 3.

3.6.6.2 Frailty Rating

Individuals were defined as moderately or severely frail according to the Clinical Frailty Scale (Rockwood et al., 2005) to reflect clinically assessed vulnerability. Those that received seven hours per week or more, of formal or informal care to assist with activities of daily living were considered psychosocially dependent.

3.6.6.3 Inclusion Criteria

Those age 75 years and over, assessed as moderately or severely frail by the senior physician involved in their general care at the day hospital and receiving seven hours per week or more of formal or informal care.

3.6.6.4 Exclusion Criteria

Cognitively impaired individuals being those with a Mini-Mental State score (MMSE) (Folstein, Folstein, & McHugh, 1975) of less than 24 were excluded. Those with active, progressing cancer were also excluded from the study as their experiences may be largely moderated by the trajectory of that illness, and they may be in receipt of palliative care services from the more developed cancer care system.

3.7 Process of recruitment

3.7.1 Identifying participants

Participants were identified by the geriatrician involved with their care at the day hospital as being moderately or severely frail according to the Clinical Frailty Scale (see appendix 13 for details), as receiving seven or more hours of care per week and a MMSE score of 24 or above.

3.7.2 Reviewing records

Once a participant was identified by the physician, nursing staff ascertained information such as Body Mass Index (BMI), age and social background in order to gain a basic understanding of their social circumstances and to exclude those being treated for on-going active cancer. There was no attempt, to check these records or to

verify what participants later told me. I did not take note of medical diagnoses, but participants themselves could inform me of any symptoms or diagnoses that were considered relevant to them during the course of the interviews.

3.7.3 Recruiting the older participant

Once identified, potential participants were approached by a member of the day hospital staff, either a staff nurse or a doctor and asked if they would be willing to speak to me with regards to the study. I was introduced as a researcher working at Edinburgh University and that I was looking into the experiences and needs of older people. Following this I gave a description of the study and what it would involve should they agree to participate. Potential participants were given the opportunity to ask questions and took an information sheet (Appendix 4) home to read and discuss with others if necessary. I would ask if I could telephone them 48 hours after the initial meeting where they could ask any further questions they had at this point, and could make a decision as to whether to enter the study or not. If, at this stage, they agreed to take part, I would arrange a date, time and place to meet for the first interview. On meeting for the initial interview I would ask if they had any further questions or doubts. If willing to continue they then read through the consent form and signed if they agreed with all sections. Participants had the information sheets available to them and had opportunities to ask questions on at least three separate occasions. If a participant nominated a family member I would ask if they could share the information sheet with them. Alternatively if the nominated carer was present at the first interview they were given an information sheet at that stage.

3.7.4 Recruiting informal carers

The term informal carer was used here to refer to another individual who is involved with or closely aware of the day to day circumstances of the older person on a personal rather than on a professional or paid basis. The purpose of recruiting this person was to provide the perspective of an outside yet closely involved other.

At the time of meeting the participant in the day hospital and explaining the study I would ask if there was anybody that was involved in their lives on a personal level,

be it a family member or a friend that they felt would be willing and able to also participate in the study and talk about the older person's current circumstances. I did this at this stage to ensure that participants had a chance to consider whether they were willing to ask such a person prior to agreeing to take part. Once a participant agreed to take part they then provided contact details of this person and written consent to contact them at the first interview.

3.7.5 Recruiting professional carers

Professional carers were sought at the first interview also. I asked the older person if there was anyone who they felt was involved in their health or social care or day to day life on a professional or paid basis and could offer an insight into their experiences or needs. If a participant was unable to easily nominate someone at the first interview I did not push the issue but proceeded with the interview to see if anyone emerged in the process and asked again at the following interview. If a professional was nominated but was not able to participate I asked for another person at the subsequent interview.

If a professional was nominated I gained written consent to make contact. I then sent letters to the individuals inviting them to participate. If they agreed then consent forms were posted and once received back the person was contacted and an interview arranged.

3.8 Data generation

3.8.1 Qualitative Interviews

Qualitative research uses a variety of techniques such as focus groups, interviews, diary keeping and ethnographic observation in order to generate data. For the current study, my underlying philosophical underpinnings guided me towards interviewing as a method frequently used in hermeneutic epistemologies (Kvale & Brinkmann, 2009). In considering other methods for eliciting narratives, I believed that diary techniques would be overly onerous and would place too much of the responsibility

on the participants at a stage when they were potentially unwell and weakened. Focus groups could have been useful for investigating shared understandings and may have provided the opportunity for participants to validate each other's experiences. However, focus groups could not meet the aim of investigating the holistic, multidimensional experiences of individuals over time.

As humans generally communicate in everyday life through conversation, and research interviews can be viewed as an extension of this (Mishler, 1986), I considered interviews as the best approach to understand the experience of frailty from the perspective of an older person. Suitably, Kvale describes the qualitative research interview as attempting to "understand the world from the subject's point of view, to unfold the meaning of their experiences, to uncover their lived world" (Kvale & Brinkmann, 2009: p1). Mishler further argues that the in-depth, semi structured, as opposed to structured or survey based interview strengthens the participant's voice and facilitates a contextualised understanding of their experiences and problems in their own terms (Mishler, 1986). However interviews are not simply a method for gaining answers from the interviewee. They are regarded as an interactive activity, where knowledge, as opposed to objective truth, is constructed in the interaction between the participant and interviewer and knowledge is dependent on the social relationship between the two (Kvale & Brinkmann, 2009). Such an approach then resonates with a constructionist, hermeneutic stance, and to the aims of the project and was adopted in order to generate data that could give rise to the rich contextual accounts of living with frailty towards the end of life.

Roulston explains criteria for ensuring interview rigour (Roulston, 2010). I will describe what these are and how I believe that I tackled them. The first involves understanding the linguistic and cultural norms of the community to be investigated in order to be understood by participants. I believe that I can claim a degree of this understanding, having spent years working as a nurse in a variety of settings and later as a psychology research assistant working on a project with older adults with memory difficulties and their informal carers. The second is appropriateness of the methodology and is explained in my adoption of a constructionist stance and focus

on narrative. The third involves ensuring reflexivity within the research process, which is inherent in the study description and within the method of analysis chosen. Finally analysing the interviews in a manner that understands the ‘metacommunicative’ quality of interviews was aided by an awareness of communicative features such as voice tone, inflection or body language and in close listening to audio recordings along with transcriptions.

3.8.2 Narrative interviews

Given the narrative focus of the PhD, there remains the question of how to elicit narratives in an interview setting. The actual goal of narrative interviewing has been described as generating detailed accounts (Riessman, 2008). Mishler describes how, in trying to answer questions in a way that was coherent and meaningful, participant accounts frequently resemble stories (Mishler, 1986). However, sometimes narratives do not emerge, even though they are the specific aim of the research so there are strategies that can be employed to encourage them. It is considered best to use every day, as opposed to sociological language and ask questions that are simple and easily relatable to the individual’s experiences (Elliott, 2005). Questions should aim to open up topics of investigation and allow the participant to construct answers that are meaningful to them (Riessman, 2008) and the interviewer should refrain from interrupting the participant while they give their responses (Mishler, 1986). Thus, I aimed to use open questions, to allow participants the time to fully respond before following cues or asking for elaboration or opening up further areas for discussion.

3.8.3 Interview schedules

In order to adopt the conversational approach advocated in narrative methodology, and one that would elicit stories, the aim of the interviews was to be guided by the participants. However an interview schedule (Appendix 11) was developed as a loose guide to offer some level of structure for the interview and as prompts should the conversation become halted. Questions aimed to cover the holistic model of the illness experience broadly incorporating the palliative care dimensions of physical,

psychological, social and existential experiences and needs. Further questions covered communication with professionals and health and social care services in order to explore any perceived barriers, and facilitating factors, to health and social care. This was submitted and approved during the ethical review process.

I also placed great importance on developing my relationship with participants and in developing a rapport with them. This was important not only for the function of the interview, but also in the process of the longitudinal approach where I could be involved in their lives for some time to come.

3.8.4 Subsequent Interviews

The interview guide was only used at the initial interview. Subsequent interviews aimed to explore issues that had emerged in the previous interview, to investigate change and to broach topics that did not feature highly or had been avoided, often due to their sensitive nature. In this way, each interview was able to build on the previous. I began by reading the previous interview(s) and their analysis, highlighting topics of conversation I then grouped them within the broad dimensions to develop a topic guide. I also ensured that the interview covered all of the four dimensions and aspects of communication.

3.8.5 Separate versus joint interviews

I expected that some of the older participants would opt to be interviewed together with their informal carer. Joint interviews are an accepted method of enquiry (Morris, 2001) and have been used in this form of research (Boyd et al., 2004; Cavers et al., 2012; Pinnock et al., 2011; Carduff, 2012). However, there are potential constraints to joint interviews (Morris, 2001). They may inhibit hearing open accounts both from when participants may have underlying issues that they do not wish to reveal, or are not apparent to the interviewer. They may also wish to spare each other's feelings or present a positive front. They may also be intrusive in terms of forcing discussion of issues that one member may not wish to open for conversation. Conversely, the benefits are in the capacity of joint interviews to offer insight into relationships, joint sense making frameworks and in mutual support

during discussion of sensitive topics (Morris, 2001). Finally, informal carers and core participants can offer prompts to each other that highlight issues that may not have come up otherwise, whilst the interaction alone between the patient and the informal carer can offer valuable data surrounding their relationship.

3.8.6 Ensuring informed consent

3.8.6.1 Process of consent at time point one

When I met a participant for the initial interview, I asked if they had any further questions or doubts. If they were still happy to continue I invited them to read through the consent form and, if they agreed with all sections, to sign it. Issues surrounding the capacity to give informed consent were clearly relevant to this group of individuals; however they were all recorded to be cognitively intact at the beginning of the study. It was anticipated that some participants may begin to show evidence of cognitive decline during the course of the study. I planned to carry out a further MMSE test if this proved to be the case, and consider no longer interviewing a participant at this stage.

3.8.6.2 Process of consent with informal carers

When participants had opted for a joint interview, the informal carer was present when I arrived for the interview. At this stage, I ensured that the participant checked and signed the consent form to contact carer forms before continuing. A full explanation of the study was once again given and both participant and carer were asked if they had read the information sheet and if they had any further questions. After clarifying questions both were invited to look at the consent form and sign if they were happy to continue.

3.8.6.3 Process of consent with professional carers

Once a participant had nominated a professional and signed the form agreeing that I could contact this person for the purposes of an interview, I sent out an invitation letter to their place of work. On the one occasion that the professional carer was present, I gave them an invitation letter and information sheet at that time. Once the

professional had time to look over the information and agreed to participate, I gave, or posted an information sheet and consent form with a stamped addressed envelope. Only when I was in receipt of signed consent forms did I telephone to arrange an interview.

3.8.6.4 Process at follow-up interviews

On-going verbal consent was sought at all follow up interviews. I reminded the participant of the process of the interview and what they had consented to. I asked if they were still willing to participate in the study, for their interviews to be audio recorded and for carers to be contacted. All participants were reminded at all stages that they were free to withdraw from the study at any point. No participant or carer took this option.

3.9 Conducting the interviews

3.9.1 Place

Once a participant had agreed to participate, I suggested that I could carry out an interview at the day hospital or in their own home, at a time that suited them. However, I hoped to be able to carry out interviews in a participants' own home, where they would be more relaxed and would not have to undergo the upheaval of another trip to the hospital to meet me.

3.9.2 First Interviews

At all interviews it was important that participants were not forced to talk about subjects that may be distressing, or that they were not ready to consider or discuss. Accordingly, topics of discussion were guided by participants, and exploration of issues based on cues during the interview. I aimed to begin each interview with the question 'so has it been a while since you've needed a bit more help in your day to day life?' This allowed participants to focus on the purpose of the investigation, as there was not the same clear reason for interviewing them as there may be if I was investigating the experience of a defined illness such as cancer.

3.9.3 Interim communication

I aimed to telephone participants every two months to evaluate if there had been any major changes in circumstances. These phone calls enabled me to keep up to date with the events taking place in the participants' lives and to build on, and maintain, the relationship that developed after initially meeting them and then carrying out the first interview. I planned to ask the participants if they would like me to return at that time, or if they were happy that I leave it and call again in another 2 months' time to see how they were and if any changes had taken place. Field notes would be taken during and following the telephone calls to note the overall events or main issues mentioned, and my own impressions. I did not plan to quote the words of the participants, as I did not feel that they would have been as prepared to speak to me as they had been in the interviews, and that they had not given consent for their words to be used directly.

3.9.4 Follow-up interviews

Following the initial interviews, subsequent interviews were planned to take place at around six monthly intervals to a maximum of eight month intervals and a minimum of two, depending on the circumstances of the individual.

3.9.5 Bereavement interviews

As is the nature of end-of-life research, and indeed any involving illness, there was the potential that participants would die. I felt it was important to carry out a bereavement interview with a carer for two reasons. First, it could offer an understanding of the older person's final days that would otherwise be missed. Secondly, and perhaps more importantly, I felt it was ethical, as I would have built a relationship with the carers. On hearing of a participant's death I intended to send a sympathy card and telephone the carer after approximately one month. If I heard directly from the carer themselves then I would talk with them at the time. I would ask if they wished me to come back for a final interview and allowed them to dictate when they would be ready for this to take place.

In terms of the interview content, I aimed to allow the carer to discuss whatever they felt was important before asking about any issues from previous interviews that may be appropriate to ask in the context. Again, I ensured that we touched on all the dimensions of the topic guide.

3.9.6 Professional carer interviews

Professional interviews were arranged to suit those involved. I offered to carry out telephone, or face to face interviews at the place most suited or convenient for the professional. Nominated professionals were to be interviewed at a single time point. The aim was to interview at the beginning of the study in order to offer an outsider context to frame the accounts given.

3.9.7 Leaving the final interview

At the end of the final interview I would be required to close the interview process with participants. I felt that cutting off my relationship with all participants immediately after the last interview concluded would be overly abrupt. I therefore offered feedback, either written, by telephone or face to face, at the preference of the participant, once the study was completed to offer a gentler exit to the process.

3.9.8 Sensitive Issues

First of all, although the focus of the PhD was to look at frail older people, this term was not used in any written or verbal communication with participants. My rationale was that I considered it to be a potentially ‘loaded’ term that may be upsetting, pejorative or demeaning in the eyes of the participant. Further, I believed strongly that it was not my place as a researcher to bring in a term with clinical associations for what may be the first time. In lieu of ‘frail’ I chose to describe ‘being at the stage in life when you need a bit more help with day to day life’. During the interview process I aimed to remain open to potential signs of distress or difficult areas of questioning and remain sensitive to how these were handled.

3.9.9 Field Notes

Field notes were to be kept following all communication with participants. I would note down my first impressions of what I saw and what I heard. Any hunches at this stage these would be noted along with any dominant emotions that I felt on leaving.

3.9.10 Welfare of Participants

Clearly the welfare of participants was of paramount concern and I felt responsible for the moral and ethical decisions taken. Throughout the interviews I was aware of monitoring signs of distress, either from the interview process itself, or in areas where what a participant told me could imply that they may be at risk. Accordingly, I was prepared to terminate the interview if requested, or if the participant became distressed or tired. In cases of general concerns over health or well-being, I would ask permission to contact the General Practitioner or encourage the participant to do so or speak to the nominated informal carer. Such considerations also permeated decisions to begin an interview or to reschedule. There was also a possibility that on meeting a participant for an interview, to carry it out or to continue with it once begun, would be inappropriate.

3.9.11 Welfare of myself and the transcriber

This study involved my getting to know the participants, their families and being involved with their lives in detail. I expected that I may become emotionally involved and invested with the participants and that what they told me could be distressing. Thus I planned to access the counselling services of the university should I find the research becoming overly stressful and to offer support to any transcriber that may help with this process. In order to maximise my own safety, before I set out to carry out an interview, I left details of the address that I was going to with another person who I then telephoned once the interview was complete.

3.10 Analysis

In describing the plan for analysis I will outline what I aimed to do, explain the pragmatic decisions that I took in the practical process of the work and how the resulting analysis was conducted.

3.10.1 Transcription

All participants were given a code number and references to identifying features such as names and places were anonymised. For each transcript I listened to the audio recording while reading through the text to check for any discrepancies or missed nuances, and to fully hear the participant's voice again. Interviews were transcribed by myself or an experienced transcriber and were done verbatim with the use of local colloquialisms, long pauses and laughter, or audible crying was noted so I could take account of the non-verbal communications and contextual details. While I agree that it is not possible to completely capture the full essence of the contextual details of an interview (Green 1997, Bird 2005, McLellan 2003), I believe that listening back to the recordings enabled me to partially return to the encounter. In this way I was able to realise or remember the significance of what was transcribed, the pauses and non-verbal interactions and overlaps between speakers.

3.10.2 Narrative Analysis

Analytical approaches for carrying out a narrative analysis of textual data have been separated by Riessman into thematic, structural or dialogic/performance methods (Riessman, 2008). Thematic analysis looks at 'what' is said, but it has been criticised for ignoring the role of the researcher in constructing the narrative, and for limitations in considering context. Structural methods investigate 'what' is described but also take account of 'how' the content is organized. However, these again pay little attention to impact of the relationship between the speaker and the listener, or to the societal contexts in which the narrative is produced. Finally they can have a tendency to fragment data from its context which can result in lost meaning (Riessman, 2008; Mishler, 1986). A dialogic/performance method is described as

selecting elements of thematic and structural styles, and adding other dimensions. These crucially require close attention to the role of the researcher and the social circumstances and setting in how the narrative is produced and then analysed.

One such method is the Voice Centred Relational Method (VCRM) which was initially devised by Brown and Gilligan, who studied girls' accounts of their lives development as they negotiated adolescence (Brown & Gilligan, 1992). The method has been further used and written about in the sociological research. It has been described as being able to bring data analysis from implicit to explicit, as beneficial for ensuring adequate reflexivity and in enabling the researcher to hear the different voices used by a narrator in the different relational contexts of their lives (Mauthner & Doucet, 1998). This relational element is considered as central to the VCRM as it allows a researcher to describe "a number of slants on the same narrative material" (Byrne, Canavan & Millar, 2009). Thus, the different dimensions of experience voiced by frail older people may be apprehended, while the possibility of fragmentation is minimised by keeping the narrative whole and maintaining the integrity of the story.

Three to four distinct close readings are advocated, where the investigator listens to the participant's voice in its relational contexts that is in relation to the self, to relationships with others and in relationship with the wider social and historical context. A key advantage of using the VCRM is that it promotes a depth of involvement with the data. It forces the analyst to think across the key areas of overall story and really hear the voice of the individual in their relationships. The method also includes a built in reflexive component, where the researcher is required to explore their own reactions and biases to the interview. The template used for the analysis is shown in table 2 below. Therefore, the VCRM is well suited to study the holistic physical, social, psychological and existential experience of illness, although it is currently used infrequently in health research. However, Mauthner and Doucet have criticised the method for the sheer volume of time required to produce the analysis (Mauthner & Doucet, 1998). Given the longitudinal nature of the current

study, this was taken into consideration in the numbers of participants recruited, yet remained a considerable issue.

Table 2: Template for the VCRM. Adapted from Brown and Gilligan 1992.

<p>Reading 1a = Plot. Overall story that is being told by the respondent – what are the main events, the protagonists, and the subplots.</p> <ol style="list-style-type: none"> Listening to the overall story that is being told by the respondent. <ul style="list-style-type: none"> Main events Subplots Who (protagonist)(antagonists), What, When, Why, Where Recurrences <ul style="list-style-type: none"> Images, Words Metaphors Contradictions. <p>Reading 1b = Reader response</p> <p>How I respond both intellectually and emotionally. Placing myself with my own particular background history and experiences in relation to the person that I have interviewed. My own interests, biases and limitations arising from critical dimensions such as race, class, gender social location. Also track my feelings in response to the story, ‘particularly those feelings that do not resonate’ with those expressed by the teller.</p> <ol style="list-style-type: none"> Do I identify with or distance myself from this person and how? Are my experiences different or the same and how? What do I find confusing or puzzling? What do I find certain or clear? Does the story make me feel happy, amused, pleased or upset, disturbed, angry?
<p>Reading 2 = Reading for the voice of the ‘I’</p> <p>How the respondent experiences, feels and speaks about herself. Use of ‘I’, ‘we’, or ‘you’ in talking about themselves. Highlights where the person might be struggling to say something either emotionally or intellectually. Where the person shifts between I, we, or you signals changes in how the respondent perceives and experiences herself.</p> <ol style="list-style-type: none"> How does the participant experience, feel and speak about herself? <p>How does this change?</p> <ol style="list-style-type: none"> How does the carer experience, feel and speak about herself? <p>How does this change?</p> <ol style="list-style-type: none"> How does the carer experience, feel and speak about the participant? <p>How does this change?</p>
<p>Reading 3 = Reading for relationships (and broader social networks)</p> <p>How the person speaks about interpersonal relationships with partner, relatives, children and the broader social networks of life work and parenting.</p> <ol style="list-style-type: none"> What are the significant relationships in the narrative? Relationships with health care professionals? Relationships with family?
<p>Reading 4 = Placing people within the cultural contexts and social structures</p> <ol style="list-style-type: none"> How the respondents accounts and experiences are within broader contexts <p>Social</p> <p>Political</p> <p>Cultural</p> <p>Structural</p> <ol style="list-style-type: none"> Ideology <p>Dominant or normative expectations</p> <p>Moral terms – should, ought, right, wrong, good, bad.</p> <p>Social structures and ideological forces that may constrain and/or enabling.</p> <p>Troubles as personal or private or as more public or socially located?</p> <p>Which voice is dominant? The moral, societal, personal.</p>

3.10.3 Thematic Analysis of professional interviews

Although I had planned to carry out a VCRM narrative analysis for the professional interviews, they tended not to emerge as stories, although there were, at times, narrative elements. Initial attempts to apply the VCRM, for the sake of consistency, did not work with the data. Instead, the interviews were analysed ‘in relation’ to the participant’s story looking for themes that differed or concurred with or that provided clarity to the older person’s account. These were incorporated when the longitudinal analysis was complete. As most of the interviews were relatively short in length, I was able to take the themes and issues and weave them into the longitudinal stories of the older people.

3.10.4 Longitudinal Analysis

3.10.4.1 Managing the data

In planning the analysis for the PhD I had assumed that I would use Nvivo or a similar software package in order to store, organise and retrieve data from this large data set. However, whilst attempting to use Nvivo for analysis, I found that it would not be appropriate. While there may be ways to use the VCRM in Nvivo I found that too much fragmentation and de-contextualisation was occurring for my aim of looking at an individual case over time, but also countering the point of the voice centred method. Looking at a coded item in Nvivo did not readily relate to the form and content of the narrative. Although the negative side of such a decision meant that I had to manage the data set in some other way, I knew it would enable me to maximise the utility of the interviews. Additionally, I found that although the data set involved a large number of interviews, their interrelated nature was helpful. For example, sets of interviews, centred on 13 individual frail older people, were clearly woven together and demarcated by different time points which allowed me to actually work through individual narratives with relative ease. For each interview I used a template where the interview was on one side while the various stages of the VCRM were written on the other side. I then completed a summary analysis and kept these together in data sets of time points centring on each older participant.

3.10.4.2 Analysing across time

In order to bring together the data set for each participant, a case study approach (Thomson, 2007) was chosen to allow each individual story to emerge, rather than to look for overarching general themes. I felt that this approach would allow the participants' individual voices to be heard within the specific contexts of their lives and histories and avoid, as much as possible, fragmenting their accounts. Looking at how to bring stories together, I looked at the original VCRM method developed by Brown and Gilligan, which was carried out longitudinally with young girls' repeated interviews over a number of years. No explicit process was found, as to how this was actually done. I next considered guidelines for longitudinal analysis (Saldana J, 2003; Lewis, 2007) and used elements of these approaches to inform the process.

On a practical level then, when I began to analyse a second interview, be that a separate carer interview or a second participant interview, I would re-read all previous transcripts and analyses in order to familiarise myself with the overall story again. I then took the first analysis, bringing out the themes and issues emerging from it. I followed this by bringing in each subsequent interview analyses looking at what had remained consistent, what had changed, and how it changed. The analyses were plotted visually according to the four readings of the VCRM on a piece of A2 paper divided into wide columns for each interview. This allowed me to draw links across time, see how issues inter-related and overlapped and brought together the story of the individual's experiences as told to and constructed with me over the period of time.

3.10.4.3 Presenting the stories

The stories are presented in three groups that share a similar thread. Each story is presented chronologically, beginning with a description of the older person and my initial encounters with them. I then recount the story that I was told by the older person, and their carers, from each interview as it occurred and relating change as it occurred over the time that I was involved with them. Interim details that link between time points are provided by the interviews, the interim phone calls and from meetings, although no quotes from these latter communications are given. Themes

from the professional interviews are interwoven where appropriate, to add background and depth to the story. Each story is followed by a brief summary. Each group of stories are then summarised together explaining how they fit together and are followed by an explanation within a narrative framework.

3.11 Summary

In this chapter I have provided the theoretical framework in which the study was situated and have described how the research was designed in order to maximise the transparency of the methods used. In the following chapter I will continue to ensure transparency by describing how the study was carried out.

Chapter 4: Conducting the study

I will provide, in this chapter, an outline of the practical process of the study, an overview of the participants and the interview process and the chronology of the interviews.

4.1 Recruiting the participants

All the participants who were approached by the day hospital agreed to speak to me. Two later declined to take part in the study. When they were entered into the study no participant or informal carer withdrew. I recruited eight female participants. Four lived alone and four co-habited. I recruited four males. Two lived alone and two co-habited. I achieved the number of eight females prior to the required number of males so recruitment continued over a period of weeks until I was able to recruit the remaining men. As I described in chapter 3, to ensure longitudinality I re-recruited a new participant for every one that undertook only one interview. This only happened on one occasion when Mrs Baxter died before I was able to return to see her again. In this case I recruited another participant of the same gender although not of the same co-habitation status.

Details of the participants are shown in table 3. There were a total of 13 participants of whom five were male and eight were female ranging in age from 76 to 91 at recruitment. Seven participants lived alone, two with an adult child, three with a spouse and one with a sibling. Nine were widowed, three were married and one was unmarried. By the end of the interview period five participants had died and two had moved into a care home. There were three participants with a visible medical problem and who chose to talk of their Parkinson's disease, osteoarthritis and diabetes which had led to a limb amputation. Beyond this, participants talked of health problems when they were relevant to their lives and are detailed in the stories they gave. I also aimed to include those from a variety of social economic backgrounds. However this occurred quite naturally with participants ranging from the professional to manual labour backgrounds. I cannot be sure that I was able to adequately mirror these groups in relation to the actual population demographics of

frail older adults but it appeared that no single SES group was more evident than another.

It should be mentioned that it became apparent that co-habitation partners varied vastly and their situations could not be regarded as comparable. For example, one lady lived with her two adult children while another with her very frail and disabled husband who she continued to help care for. Similarly the input from a non-resident carer was also very heterogeneous ranging from a weekly visit to being present with the older person for the majority of every day.

At recruitment, eleven of the participants lived in bought properties, one in sheltered housing and two in council accommodation. BMI (Body Mass Index) and MMSE scores are given along with the living circumstances of the older person to give a flavour of their situation.

Participant	Gender	Age	BMI	MMSE	Living Status	Marital Status
Mrs Andrew	Female	84	21	26	Offspring	Widowed
George	Male	76	25	29	Spouse	Married
Mrs Wood	Female	77	28	29	Alone	Widowed
Miss Pegg	Female	88	24	29	Alone	Unmarried
Mrs Baxter	Female	85	18	29	Spouse	Married
Mrs Ritchie	Female	92	18	25	Sibling	Widowed
Mrs Howie	Female	90	28	29	Alone	Widowed
Mrs Pryor	Female	85	27	29	Alone	Widowed
Mr Mackie	Male	91	25	26	Alone	Widowed
Kathleen	Female	84	17	25	Spouse	Married
Mr Robson	Male	81	24	27	Offspring	Widowed
Mr Hughes	Male	91	23	25	Alone	Widowed
Mrs Gray	Female	90	30	29	Alone	Divorced

Table 3: Participant details: pseudonym, gender, age, living status, marital status

All participants nominated an informal carer who agreed to participate in the study. Of these, seven were daughters, two were sons, two were spouses, one was a niece and one a daughter in law.

4.2 The interviews

4.2.1 Location of the participant and carer interviews

Although I offered to undertake interviews at the day hospital only one participant opted for this for the first of three interviews. One interview was carried out in a long stay hospital ward, as the participant requested to remain there and not to undergo a tiring relocation to another room. Another two were in the participant's room in a care home. The remaining interviews with the older person or joint with participant and carer were carried out in the older person's home. Of the carer interviews two were undertaken by telephone, one due to the time pressures on the older person's daughter and the other because the nominated son lived in another country. The remainder of the interviews were carried out at the carers' homes. I believe that the interviews that were carried out in the home environment were more comfortable for all as they encouraged a more natural flow of conversation, and allowed for the benefits of non-verbal communication between myself and the participant.

4.2.2 Timing of the participant and carer interviews

I aimed to conduct interviews on a six to eight monthly basis, but opted to be flexible with timing and bring forward follow up interviews should circumstances change for the older person, or delay follow up should all remain stable for them. Additionally, I asked at each interim phone call if participants preferred me to return sooner or later. Some participants went 'off radar' for a period of time due to hospital admissions or other difficulties with maintaining contact. If this was the case, and I was unable to speak with the older person at an eight week interval, I considered this a break in follow up and added this on to the end of the timescale.

There was a prolonged break of 14 months between the first and second interviews for Mr Robson, as two arranged interviews were not carried out as he had been admitted to hospital. I subsequently, and unsuccessfully, tried to trace him in the hospital or to contact him by telephone. I eventually opted to visit him in person at home. There was also a prolonged break of 14 months between interviews two and

three for Mrs Pryor as there were two occasions where interviews were booked but on my arrival I found that she had been admitted to hospital. On the third occasion when I met Mrs Pryor for a final interview she requested that I stay for a chat and undertake the interview when she was settled into the care home where she subsequently moved to three months hence. These two participants completed a final interview 21 months after their first. The remainder were followed between four and 19 months with an average of 14.5 months. See table 4 for details of the interviews for each participant. This flexibility allowed me to adapt to changes in the circumstances of the older people and to capture changes as they occurred. It potentially helped to retain the participants in the study and facilitated the relationships that I build with them as I able to adjust our meetings into their lives.

4.2.2.1 Interim communication

In practice, I found that unless there had been major events taking place, most participants told me that all was well and that they were doing fine. Calls were generally short and to the point, with few exceptions. There were some participants who were more comfortable with talking on the telephone than others. Notably I found the males to the point and perfunctory. There were two participants whose poor hearing made talking on the telephone difficult and so I requested to speak with their nominated carer instead. Participants agreed that this was fine. On other occasions, although I telephoned the older person's home, it was the carer that answered and I spoke with the carer in their place. In these circumstances I would converse with them and then ask if the older person would like to talk with me. When it was a spouse that I spoke with, all were content that the carer had spoken for them, however, when I spoke to offspring I often found the older person wished to talk to me.

4.2.2.2 Where telephone contact was not possible

Some of the participants had so many visits to hospital and changes in residence that it made them very difficult to contact. I decided to call their nominated carers who I had also interviewed in order to find out their whereabouts. There were occasions where I opted to visit the participant in hospital as a means of maintaining contact or

to arrange a follow-up interview at a later stage. These visits were arranged with hospital staff and I was uniformly greeted gladly by the older person. There were at times, however, where it was nigh on impossible to stick to any form of regular contact and interviewing as a participant was admitted to hospital, moved wards or discharged to home or to somewhere else.

4.2.3 First Interview process

Having explained the purposes of the study, gone through the process of consent I told participants that I wanted to hear their story. Often, participants would launch into the interview before I had the chance to switch the recorder on or ask an opening question. Perhaps the use of the word story primed them to begin telling their tales. Once the participant began to talk I allowed them to continue, following their lines of conversation.

4.2.3.1 The first Interviews

A total of 21 first interviews were carried out five of which were joint with carers and eight were undertaken separately. The interviews lasted between 25 and 95 minutes for the single interviews and between 30 and 55 for the joint. Following the first interview one participant died and one moved to a care home.

4.2.4 Follow-up interview process

I began each follow-up interview by asking how the interviewee had been since my last visit in order to allow them to talk about what, if anything had changed. If they did not remember what we had discussed I would briefly remind them of what had been happening at that time. I would follow from this by opening up issues that had emerged from their previous interviews and analyses, as well as emerging issues from the study generally, and ensured that we had again touched on all the dimensions of the interview topic guide.

4.2.4.1 Second interviews

A total of 18 second interviews were carried out, of which six were carried out jointly with carers while six were undertaken separately. Two of the separate interviews were bereavement interviews. The interviews lasted between 30 and 95 minutes for the single interviews and between 35 and 70 minutes for the joint. Following the second interviews three participants died and one moved to a care home.

4.2.4.2 Third interviews

A total of 15 third interviews were carried out, three of which were joint with carers, five were undertaken separately and two were with carers only. The daughter of Mrs Ritchie requested that I not return a third time for a third participant interview due to her mother's cognitive decline. Instead, I carried out a third carer interview. Mrs Ritchie had instructed me to make all the phone calls and arrangements through her daughter, so I considered that the request was in the interests of the older person. The other carer only interview was a bereavement interview. The interviews lasted between 35 and 85 minutes for the single interviews and between 30 and 35 minutes for the joint. Following the third interview one participant died.

Participant	Int 1	Months to int 2	Int 2	Months to int 3	Int 3	Prof Int	N
Mrs Andrew	Separate	8	Joint	8	Joint	Yes	5
George	Joint	10	Joint	8	Joint	Yes	4
Mrs Wood	Joint	8	Joint	8	Separate	No	4
Miss Pegg	Separate	9	Separate	10	Separate	Yes	7
Mrs Baxter	Separate					No	2
Mrs Ritchie	Separate	6	Separate	6	Carer only	Yes	6
Mrs Howie	Separate	7	Separate/ Bereave	[3]		No	4
Mrs Pryor	Separate	7	Separate	14	Separate	Yes	7
Mr Mackie	Separate	10	Separate	8	Separate	No	6
Kathleen	Joint	8	Joint	[4]	Bereave	Yes	4
Mr Robson	Joint	14	Joint	7	Joint	No	3
Mr Hughes	Joint	4	Joint	8	Separate	Yes	5
Mrs Gray	Separate	8	Separate/ Bereave	[3]		Yes	5
Total	21		18		15	8	62

Table 4: Number of the interviews for each participant

4.2.5 Timing of the carer interviews

It was my intention to carry out carer interviews as soon after the participant interview as possible. In practice this proved extremely difficult as four of the carers struggled with multiple commitments and to find the time for an interview. Three of these women held down professional jobs, one requiring regular foreign travel, while three of the four also had families of their own with significant responsibilities. I was very aware of not wanting to add to the pressure on their already busy lives. Consequently these interviews took place an average of 10 weeks after the interview with the older person. The remaining carer interviews were undertaken an average of 2 weeks after interviewing the older person. Only one interview took place before the participant interview. This was with Mrs Pryor who I visited in a long stay ward for an interview, but she requested that I delay carrying it out until she had moved to her care home. I had already arranged an interview with her daughter in law the following day who was keen that I keep to this arrangement.

4.2.6 Bereavement interview process

On the occasions that an older participant died and I contacted their carer, the carers talked to me at length on the telephone about their loved one's death and asked unprompted, if I wished to do another interview with them. All the carers agreed that this would be suitable so a further interview was arranged. Accordingly, I was reassured that these carers were comfortable to participate in a bereavement interview and these proved important for describing the end point of the story for their relatives and provided closure on the research process. Bereavement interviews were generally distressing for both the bereaved relative and myself and so I allocated for much more time in a visit. I sat with the carers and talked after the recorder was switched off, for as long as they seemed to wish me to, and offer an ear to listen and to ensure their emotional well-being before I left. I further believe that this opportunity to talk about the death of the older person was welcomed by those that undertook a bereavement interview.

4.2.6.1 Bereavement Interviews

A total of three bereavement interviews were carried out. Of these, two of the older participants Mrs Grey and Mrs Howie died following the second interview but prior to the separate carer interview so the second carer interviews with their daughters became bereavement interviews. The third followed two joint interviews so the bereavement interview was the third with Kathleen's husband Robert. These lasted between 30 and 95 minutes. One further carer was not contacted for a bereavement interview as I had just carried out a telephone interview with him some weeks previously and he lived in another country. The final participant died shortly after the third interview with him and his daughter who called to me tell me that her father and died and gave me details of how this had happened.

4.2.7 Professional carer interview process

In practice it proved difficult to recruit professionals and carry out interviews at the start of the study for a number of reasons. Pragmatically, most participants struggled to name somebody who was closely linked to them from a professional point of view and the process of nominating someone often needed revisiting at follow up interviews. Even when a professional was interviewed, their ability to discuss the older person varied considerably. Also gaining contact with professionals was a lengthy process. My invitation letters were rarely replied to and some professionals, when I managed to contact them then declined to take part. I then asked the older participants at the follow up interview if there was anyone else that could be nominated in their place and started the process again. Even when verbal agreement was given, it often took a further period of time to arrange an interview as I had to understandably fit in with busy professional schedules. Interviews were subsequently undertaken at varying times in relation to the chronology of the participant.

4.2.7.1 Professional carer interviews

Professional interviews ranged from shortly after the first participant interview to some weeks after the second. One professional was nominated at the second interview and by the time I was able to contact her, gain agreement and arrange to

meet me the older person had died suddenly four days before. Four participants nominated an agency carer, of whom two agreed to be interviewed. Two participants nominated the same agency carer who did not keep the appointment for the interview and was not contactable thereafter. Both the participants had previously nominated the same GP who refused to participate. One further participant nominated a GP as a professional carer who refused to participate. Of the professionals that agreed to participate five were GPs, two were agency carers and one was an Occupational Therapy assistant at the day hospital. Two participants were unable to nominate professional at any of the three interviews. Two interviews were carried out over the telephone, one at the professional's home with the remainder were undertaken at the professionals' place of work. These ranged from 10 to 55 minutes in duration.

Participant	Carer	Relationship	Professional	Agreement
Mrs Andrew	Elizabeth	Daughter	GP	Yes
George	Alice	Spouse	Agency Carer	Yes
Mrs Wood	Marjory	Daughter	GP, Agency Carer	No, No
Miss Pegg	Mrs Brunton	Niece	GP	Yes
Mrs Baxter	Alan	Son	GP	No
Mrs Ritchie	Christine	Daughter	GP	Yes
Mrs Howie	Mrs Wilson	Daughter	None nominated	No
Mrs Pryor	Dorothy	Daughter in law	OT assistant	Yes
Mr Mackie	Gill	Daughter	GP, Agency Carer	No, No
Kathleen	Robert	Spouse	GP	Yes
Mr Robson	Gary	Daughter	None nominated	NA
Mr Hughes	Gillian	Daughter	GP	Yes
Mrs Gray	Alison	Daughter	Agency Carer	Yes

Table 5: Nominated carers, pseudonym, relationship and nominated professional

4.2.8 Leaving the final interview

At the conclusion of the final interview I offered to provide feedback either written, by telephone or face to face at the preference of the participant, once the study was completed. I thought that this would offer a gentler exit to the process however parting was still often quite heartfelt as I had developed a unique bond with those that I had interviewed. Some carers in particular asked if they could phone me in the

event of any changes in the older person's circumstances. I agreed to these requests but have only been phoned when an older person died.

4.2.9 Sensitive Issues

Although I had planned how to manage sensitive situations there were unexpected issues. Specifically it was clear that I had to handle issues surrounding the end of life very carefully as I was not dealing with a group of people who had a terminal diagnosis. Similarly I found discussion of nursing homes was an emotive topic and had also to be handled with care. Participants associated me with the day hospital and health care services and could think that I was evaluating them or knew information that I did not regarding their physical health and prognoses for the future or indeed their need for a nursing home or care home. However, the conversational style of the interviews and the relationship that was built up with participants enabled a compassionate platform from which to handle difficult or sensitive areas. If a participant became distressed I would offer to terminate the interview and would follow their requests. Only on one occasion did a participant ask for the interview to stop, when broaching a broader family issue that he found distressing. I immediately ceased recording and ascertained at what point he wished me to delete the interview. I stayed with him for some time after the interview ceased and he continued to discuss the issue although nothing of it was brought to the PhD.

4.3 Field Notes

These ranged from contentment or even elation following interviews where participants had been very friendly, forthcoming and good storytellers, to relief, guilt and deep sorrow. These aided in the process of reflexivity towards the interviews and the analysis. Following telephone conversations I noted down details of what I was told and how the interaction unfolded, whether it was a comfortable telephone conversation or otherwise. These formed my understanding of the participant's situation as it evolved. Notes were not taken during the interviews as I believed that this could interrupt and inhibit natural conversation. I did, however, jot down words that acted as cues to return to a topic later in the interview.

4.4 Welfare of participants

There were only two incidents where the participant became overly drowsy during the interview and I opted to terminate the process at that point. Another occasion where I had arrived at a hospital to carry out an interview, I found the lady in question to be lying comfortably drowsing in her bed. She wanted to talk to me so I stayed with her for about 30 to 40 minutes but I decided not carry out an interview but to return another time. The occasion where I was concerned about welfare I was able to raise the concerns with the informal carer and the care staff in the hospital or care home. There was one occasion where I was concerned about a bereaved relative but was able to pass my concerns to the GP who was due to visit him later the same day. I also telephoned a week later and spoke to the gentleman. He told me that he was being well supported by his GP and family who were visiting him regularly.

4.4.1 Welfare of myself and the transcriber

As expected I became attached to most of the participants and struggled a great deal in witnessing the degree of suffering that was, at times, expressed by participants and their carers. I often experienced guilt on leaving a lonely individual and felt worry regarding the wellbeing of those that I felt were particularly vulnerable or less supported. This was highlighted during the two particularly cold and snowy winters that the study period covered when I was aware that transport chaos would have played havoc with care services getting to the participants. There were times where I felt like I had to 'sit on my hands' to stop myself from overstepping my role. For example I had a strong desire to take George, who had no family other than his disabled wife, to a football match as this was such a strongly yearned for desire on his part. I also frequently felt the desire to physically step in and help an individual and there were periods where, on a minor level, I could not resist this and asked if they would like me to wash the dishes that were at the sink or make a cup of tea and some toast. However I was fortunate to share a small office with another PhD student researching a similar area and we were able to offer mutual support. Similarly I was able to talk with the transcriber and discuss her reactions to distressing interviews.

Supervision meetings also provided opportunities to discuss difficult issues and counselling services of the university was always open to me.

4.5 Summary

In this chapter I have provided the practical details of study including a description of the participants recruited and the interviews carried out. In the following chapters I will recount the stories of the frail older people that emerged from the analytical process.

Chapter 5: The Tragic Narrative: The lost self

The following chapters will describe the stories told by the participants. The stories will be told chronologically according to what happened to the older people. Interviews with carers and professionals will be woven through the narratives to provide context, explanation and details of events that occurred.

Using Frank's typology of illness narratives (Frank, 1997) the stories were mixed. Participants experienced periods of chaos, periods of restitution and periods of quest as they moved through the changing landscape of their lives. Given this range and fluctuation within and between the narratives these were then considered with recourse to the theories of illness narratives. These are narratives at the personal level of loss of self (Charmaz, 1983; Charmaz, 1995) and narratives at the societal level according to their core structure (Bury, 2001). How these are appropriate to the stories presented here is explained at the end of each chapter.

I will present the stories in three groups, the tragic narrative of the lost self, the regressive narrative of maintaining a tenuous hold of the self and the stable narrative of holding on to the self. I will begin with the stories of three participants who seemed to lose their sense of self, Mrs Howie, Mr Hughes and Mrs Gray. All three of these participants died during the course of or just after the period of interviews. All of them lived alone and were supported to varying degrees by their adult daughters who they nominated as informal carers.

5.1 Mrs Howie

‘The story of my life. As I said, I didn’t think I’d live to this age to finish up like this.’

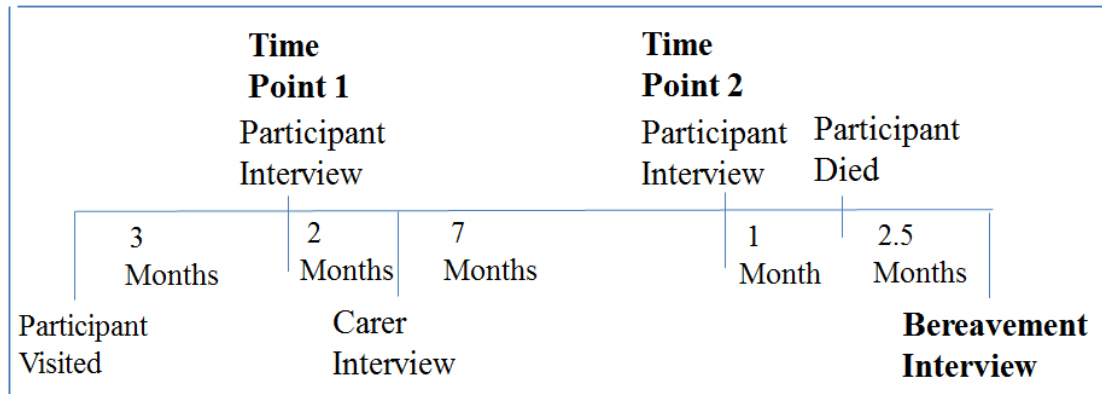


Figure 9. Time line for Mrs Howie

I interviewed Mrs Howie twice although I met her on 3 further occasions as I attempted to stay in contact with her during periods of hospitalisation and change of living environment. I separately interviewed her daughter (Mrs Wilson) twice. The first was a telephone interview as Mrs Wilson struggled to find the time to meet with me during the chaos of that period, while the second was a bereavement interview at Mrs Wilson’s home some weeks following her mother’s death. Mrs Howie was never able to name a professional whom she felt was involved in her care, because in the months that I knew her she moved residence twice and spent time in three different hospitals. All homes and hospitals were in different parts of the city and thus Mrs Howie was under the care of many different health care teams.

I met Mrs Howie initially at the day hospital where she had immediately taken my hand in hers, patting it warmly in her lap as she chatted for some time about her family and her life. She joked and bantered with me and asked all about my life, taking an interest in my circumstances and connecting with my role as a mother. She had fallen some weeks previously and was experiencing ongoing pain in her back that she hoped would soon resolve. Mrs Howie’s story had no clear starting point or cause rather her daughter (Mrs Wilson) described recent months of chaos where her

mother had repeatedly experienced falls and periods of illness with multiple emergency calls and admissions in and out of hospital. Mrs Wilson told me how she had felt lost in the chaos *'I'm quite confused about [all the events] to be honest, where they all fell in I've been going backwards and forwards so often,'* and that nobody seemed to be able to help her. *'I've had to find everything out by myself let's be honest (OK) I really find that you know, there is absolutely nothing'.* This was perhaps reflected in Mrs Howie's inability to nominate a professional whom she felt understood her circumstances.

Our first interview was arranged yet postponed as Mrs Howie was admitted to hospital as her increasing pain was noted at a day hospital visit and subsequently found to be caused by a fracture in a lower vertebra. This admission lasted for 5 months as she contracted a hospital acquired infection in her leg and was kept in a single room, so was prevented from mobilising around the ward. I visited her there for a potential interview but she preferred that I stay to have a chat with her instead and leave the interview until she returned home. A large framed photograph on the wall of the hospital room showed her extensive family waving, smiling and greeting her through the lens of the camera and Mrs Howie talked animatedly about the people in it. She also chatted easily about her connections to the area where she lived and the people she knew there, bonding with me as this was the same area of Edinburgh where I grew up. Her home was the first floor flat that she had lived in for 30 years, remaining after her husband's death 8 years earlier. Mrs Howie did not make it back to her home but was eventually discharged from hospital to a ground floor sheltered housing flat, which was on the other side of town to where she had lived, but was nearer to her daughter who was closely involved with her life. Mrs Wilson told me that she and her brother had taken the decision to accept the sheltered housing placement without her mother's involvement while she was in hospital. She expressed guilt at having done so yet explained the decision. *'When she was in the [hospital] for the long stay, my brother and I, a letter arrived for mum.....and saying that the sheltered housing I think one of the independent ones [name] had a place so my brother and I just said yes (mm hm) and my mum was in hospital there was a letter came and I have to admit again, we wrote back and I phoned and said yes,*

mum would be interested and they sent somebody from [name of sheltered housing] out to her to speak to my mum in the [hospital]. I'm not quite sure because I wasn't there and it was found out and..... they then wrote offering it to mum and without her actually seeing it, my brother and I went out and had a look at it and decided that we were going to take it because it was a ground floor and.....we eh decorated it completely, re-carpeted, stripped the walls, new curtains everything and when she came out of the [Hospital]and.....she em.....to the house, without ever going back to her own house.'

Time point one:

My first interview with Mrs Howie took place a few weeks after she had moved to the sheltered housing. She was unsettled there still but remained chatty, engaged and engaging as she told me of her connections to her old home and surrounding community and the people she knew there, talking fondly of her friendship with a neighbour [Mr Anderson] *'I think you get used to some place and my wee next door neighbour he was a wee bachelor and he was at sea all his life and then when he came home he used to say to me "Are you making any soup?" And I made soup and I always, I kept him going in soup for his lunch. I made a different soup every week for him. He still phones me, he's supposed to come and see me but he doesn't know how to get from [his home] to here.'* Mrs Howie was feeling isolated in her new accommodation *'I talk to the walls as if they're all my best friends, what else can I do?'* yet expressed her reluctance to make new social connections there, by dismissing suggestions of going to a communal area or to any organised events, wrinkling her face at the thought and shutting down the topic.

Anna: 'So when you're saying you find it hard to, you feel a bit lonely because you can't get out and see people or do things like that, is there a dayroom round the corner?'

Mrs Howie: 'There's a day room across there'

Anna: 'What do you think would help with your loneliness do you think, what do you think could happen that might help that?'

Mrs Howie: 'I don't know'

Anna: 'Getting help to go round?'

Mrs Howie: 'I'm one of these people that it doesn't really, I'm not fussed, I'm quite happy with my own company, I'm not someone that's got to have somebody.'

I was confused by this as I had sensed that she clearly valued social interactions and connections and was also how her daughter described her, '*..she misses more than anything is seeing people and[story of Mr Thomson's visits] and I think that's missing.....where she is. She hasn't been there long enough to get to know anybody,*' further describing the importance of sociability to whom her mother was. '*Although she's lost her mobility, I think that socialising with other people will keep her going*'. Mrs Howie's sheltered housing home was not quiet, however and it buzzed with carers and district nurses who came and went during the morning that I visited. The regular intrusion was trying for her and there was a palpable sense of relief when they all finally left. Nevertheless Mrs Howie was trying to adapt to this new situation of having carers, and trying to make connections with the care staff that visited her: '*well everybody that comes in I make myself sociable with them I really do,*' and remaining hopeful for the future.

Anna: 'So have you any thoughts for the next wee while, for the future what you want to see happening?'

Mrs Howie: 'I would like to get out and about a wee bit, I'm hoping that I'll be able to'

There was an alternative future however, a move to a nursing home, to which she repeatedly voiced fierce resistance. Such a move had been suggested by a hospital consultant; however Mrs. Howie vehemently opposed the idea and expressed her intentions clearly.

Mrs Howie: 'The doctor [in the hospital] said that I had to, if I didn't shake myself, cheeky devil that he was that he would put me in a home and I said "no you won't".'

*Anna: 'Shake yourself?'*²

Mrs Howie: 'I said "I'm going home" I said "you're no putting me into any home"'

² I felt quite alarmed that Mrs Howie had been spoken to in this manner and vacillated between wondering if it was how she had interpreted what she had been told or if these words were used.

She was unequivocal. She would not go. She would refuse. Nevertheless her daughter was considering the idea, *'you know we just felt that, you know we felt well, you know is the next stop that we've got to put mum into a home'* though was reluctant to raise the issue with her mother, not wishing to be the one responsible for the decision but rather suggested that the decision should come from elsewhere. *'I mean it was well is she going to have to go into a care home and I was as the [hospital] and it's these people that should be saying whether your mum is fit to go home or not.'*³

Mrs Howie was not able to adjust much further to her sheltered accommodation as another episode of ill health saw her again admitted to hospital where she again remained for a period of months. Mrs Howie's mobility deteriorated with every hospital stay and her daughter now found her to have lost all her confidence in walking due to her terror of falling: *'really [having] the fall she'd had just literally robbed her of her confidence and to use a 4 wheeled trolley. She was terrified it would run away with her.'* By now the relationship between daughter and mother was beginning to suffer as Mrs Wilson felt the increasing strain of her mother's insecurity. *'I just feel that she has become SO dependent (mm hm) that..... there are some days that I feel that I actually resent her (mm mm) and the way things have been going recently (yes) so that's one of those things thatnot again, type of thing'*

Unable to contact Mrs Howie I visited her in the ward where she was, once more, in a room on her own. This time she was markedly agitated, her eyes darting around as she sat bolt upright almost on the edge of her seat and expressed distrust in the staff that sat outside and bustled past her room. She held my hand, as she always did although this time it was grasped tightly. Mrs Howie talked again of nursing homes

³ I wondered who should make decisions like these and where Mrs Howie's voice was in the whole thing. I realised that hers was the last view point that I was thinking about at this moment. The nurse in me wanted to see Mrs Howie safe and cared for in terms of what I perceived her needs to be rather than her wishes while the psychologist in me wanted her to make her own decisions and the daughter in me wanted to see the relentless pressure lifted from Mrs Wilson.

but this time in a manner that was pleading. She begged me to offer reassurance that she couldn't be made to go against her will betraying her fear that her refusal would not be enough and lacking the previously voiced conviction in her autonomy.

Mrs Howie's fears were borne out as she subsequently left the hospital only to fall again and be admitted to yet another hospital. Here she stayed for some weeks more before moving to a nursing home. Mrs Wilson explained how the decision was made by the hospital doctor in the face of her mother's reluctance. *'Eventually the consultant in the em [hospital] said can I speak to you, so we went away and had a long chat, and he said I think you really need to get used to the idea that your mum is no longer capable(mm hm) of staying on her own because it isn't safe, she can't go to the toilet on her own, she can't do, make herself a cup of tea, she can't get food for herself, there's nothing she can actually do he said because she's lost her ability to, to stand, to walk, so she needs to go into a nursing home. And again I said well you go and tell her and he said well I'll approach the [subject], I said because mum is absolutely adamant she's not going into a nursing home.'*

Time point two:

I felt deflated that the move to a nursing home had happened and what I found when I visited for our next interview was a very different person. She was quite indifferent to my visit and our interview was more stilted and involved empty silences.⁴ She no longer held my hand and no longer asked about me. This change was noticed by her family also. Mrs Wilson: *'my daughter said she phoned her grandma for her birthday which was February and she said oh she said she's definitely not herself mum, I said what did you notice; and she said well you know you can never get off the phone when you phone grandma and she said now it was oh yea, okay, mm mmhm, okay well I better go now. And she said you know I wasn't getting much conversation out of her at all so she said she really has completely lost interest.'*

⁴ This was quite distressing. I felt rejected and like I was just another 'worker'. I felt that I had somehow let her down.

Mrs Howie talked about moving to the nursing home and felt she had had no real say in the matter.

Anna: 'And how did you feel about [moving to the home]?'

Mrs Howie: 'Well, let's be honest, I didn't want to go but I'm falling.'

Although she had agreed to go, following a visit to the residence, that it was not her choice was illustrated by her omission of any personal pronoun to describe how she reacted to a visit to the nursing home. *Just looked at it and accepted it.* Once there, she evaluated her experiences entirely negatively and felt forgotten in her loneliness in her room at the end of a corridor *'It's after [the family] go away I feel I'm away at the end here and I'm one of the forgotten army'*. Neither did she show any signs of engaging with the residents in the nursing home but rather expressed animosity to her nearest neighbour with scowls. Even when I suggested that we go to the 'day room' for a cup of tea and cake she chose the room that was empty of others and turned away when another resident appeared. This reluctance was at least in part due to the other residents in the home with dementia.

Anna: 'OK. And is there a day room to sit in that you could...?'

Mrs Howie: 'Uh-huh, but...'

Anna: 'Are you not fancying that yet?'

Mrs Howie: 'There's so many of the women that are... well, it's not nice to say it but to me they're doolally.'

Having recognised this issue for her mother Mrs Wilson had tried to find a nursing home where there was a degree of separation between those with and without dementia.

Mrs Wilson: 'You know. I mean there were we, we ended up choosing em [the nursing home] because it seemed to have all the things there for mum, my only, they were really good, my only thing that I was slightly concerned about and my brother was the same, was we understood that it was, it is in fact split into four units (mm mhm) and we understood that people suffering from dementia, Alzheimer's, that type of thing were in separate units'

Anna: 'Yeah, cause that's a big concern for your mum, I remember that'

Mrs Wilson: 'Em but as it turned out, and we were sort of said yes, you know, well they were all split up and what have you but once mum was in it was very apparent

that in fact that it was quite a mixed bag of, of people in that unit (mm mhm) and she was quite, mum was never quite understanding of people with mental health problems to be honest with you and I said but that lady's got Alzheimer's mum; but she's, she's a lot younger than me, and I said but things like that don't pick age mum, I said it's got nothing to do with it, it's just one of these things. With her generation she really didn't understand it (yep absolutely) em and she used to get really quite annoyed, quite short, and she'd say well there's nobody worth talking to in here they're all doolally, was her own expression'

As for the care staff, she felt that she lacked anyone to engage with and was instead simply a body to be toileted and cleaned at best, *'during the day they always just come and they're always in a hurry, there are so many people needing the toilet and they just come, get you on the commode, get you cleaned up and get you off, back to your bed,'* or ignored at worst.

Mrs Howie: 'well yesterday...now, sometimes you wait a long time but nobody wants to know. I waited over three hours to go to the toilet.'

Anna: 'Uh! Yesterday? Oh dear!'

*Mrs Howie: 'And you can imagine what I was like by the time I got there, I didn't.....and they get that they just leave your buzzer ringing.'*⁵

Mrs Howie's fear of falling had intensified and I witnessed her terror of standing even with help from staff and begging for the security of her wheelchair behind her at all times. Even the food was considered unpalatable and she told me that she had lost her appetite however her anorexia extended more broadly as she refused favourite dishes brought for a family party arranged for her birthday. In the words of her daughter *'she just decided not to eat'*. Mrs Howie now simply longed for the freedom to come and go and to control her own life.

Mrs Howie: 'Oh, well I would love to be able to get out and walk about. I wouldn't worry staying in here if I could walk out that door and get a bus, have a wee wander, get a bus back again.'

⁵ This aroused deep anger in me. I was incredulous.

Anna: 'Uh-huh. And is that because you could do it yourself or because...?'

Mrs Howie: 'Uh-huh, it would bother me.'

Anna: '...or the physical act of walking?'

Mrs Howie: 'It would be a bit of both, because I can do it myself and because I can walk.'

This was perhaps highlighted by her description of spending days watching the freedom of pigeons perched on a tree outside her window, as she was not interested in any natural sense⁶, and listening to hear if buses (on which people could come and go freely) passed or stopped on the road nearby. *'I've never seen [a bus]. There could be one. I see plenty traffic passing along the road and I see the birds. And in that tree there there's very often a lot of wood pigeons, they're great big things, and there's a lot of birds in this bit over here'*. Once in the nursing home Mrs Howie she felt it was the end of the road and offered no hope for the future. *'I didn't think I'd live to this age to finish up like this'*.

Bereavement Interview:

Shortly after, Mrs Howie became lethargic and unwell and after being visited by her new GP was admitted to the general hospital. Here she was kept overnight but discharged back to the nursing home the following day being advised that the doctors could find no cause for her condition. *Mrs Wilson: 'so [the doctor] said no and eventually she got, again she said to me basically we don't think there's anything anybody can do for your mum (mm mhm) but she's very weak and even if there is anything there we don't think that because she hasn't eaten, we think that because she hasn't eaten em that she's not really going to be strong enough to, to fight it. So we think she should just go back home.'* Mrs Howie now understood that she would not get better and she returned to her residence referring to it as home for the first

⁶ Having told me about watching the birds outside her window I initially thought that she was showing an interest in them from the point of view of nature. When we went to the day room for a cup of tea after the interview finished I wanted to try to engage Mrs Howie in some way and spotted a reference book on British Birds on the book shelf. I picked it up and brought it to her suggesting that we could look up what type of birds she was watching. To my surprise she rejected the book and the idea instantly turning her head away and describing the birds as 'just big pigeon things'. It dawned on me that she was perhaps looking at them symbolically as a subconscious representation of freedom.

time. *Mrs Wilson: 'and we got back and as they were, the strange thing was, as we were going down that long corridor, just as we turned the corner, there's two or three seats where people sit (mm mhm) and there was a couple of people sitting there, the one that used to annoy mum from day one cause she always sat there, and mum waved to them and she said I'm back, I'm home, I'm back.'* She also spent some time with her nearest neighbour making peace with him, *'and the chap who lived in the room right opposite mum em, he's 97, 98, and got all his capacities as is, or abilities, em he happened to be in a room and he said, he shouted to her, oh xx so you're back again, she said yes I'm home, I'm you know, come in. So he came in and he came and he stood and he took her hand and he chatted to her (uh huh) and they had this little conversation and that was fine.'* Mrs Howie's condition did not improve and she died within 24 hours of returning to the nursing home.

5.1.1 Concluding Mrs Howie's story

Mrs Howie's wish to stay out of a nursing home was of deep importance to her. She felt she belonged in her own home and her own community, where she had thrived on her established social connections. Each step further away from this chipped away at who she was and how she had lived her life. Her sense of autonomy gradually ebbed away as her initial refusal to go to a nursing home changed to 'they can't make me can they?' to finally conceding. The one thing that she feared most came to fruition and was a loss that took away the final meaning and purpose for her as summed up after her death by her daughter. *'I think the minute she actually ended up having to admit that em the nursing home was going to be her only alternative (mm mhm) em I think she just turned off the taps.'*

While she seemed willing to consider adapting to the sheltered housing she could not live with the nursing home and viewed her life as one no longer worth living. It may be that her decision to stop eating was purposeful or a physical sequelae of her depressive symptoms but either way represented profound unhappiness. Furthermore, given her years of living with diabetes and the subsequent influence of food on her health she must have been aware of the impact of a restricted diet which was likely to have hastened her death. While spending some of her final hours being

taken to and from hospital, spending time in Accident and Emergency and an overnight stay in a busy admissions ward seems undesirable, the admission to hospital seems counter- intuitively to have actually offered her solace. It was in hearing from a hospital doctor that there was no definable cause for her weakness and malaise that I believe allowed her to recognise that what was happening was her death. She finally knew that she would escape her confines and thus was able to find peace in the last few hours of her life.

Mrs Wilson 'I think for her personally I think she would just have liked to have passed on nice, peacefully, quietly in her own four walls (mm hm) which would have been her own flat, not even [the sheltered housing]'

5.2 Mr Hughes

'You're going over a wall or somewhere and they're on the other side'

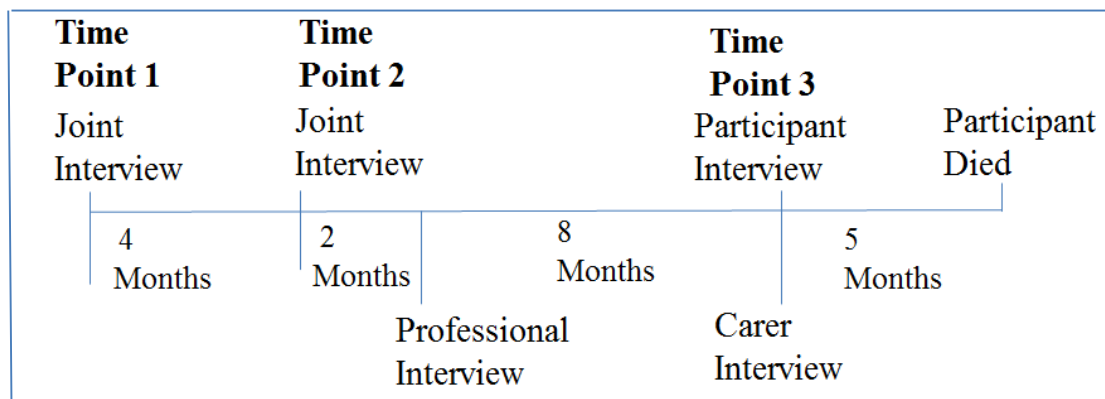


Figure 10. Time line for Mr Hughes

I interviewed Mr Hughes on three occasions. The first two interviews were jointly carried out with his nominated carer, his daughter Gillian, however the final interview was carried out alone with Gillian present but not in the room. She requested a separate interview on this occasion. I also interviewed Mr Hughes' GP who he easily nominated, and who also looked after his daughter and her family, at her place of work.

Time point one:

Mr Hughes was angry. He sat in an upright living room chair dressed in his tweed jacket, shirt and tie and outlined a very moral and principled view of the world and of himself, and described himself as 'an old soldier'. He had served in the Far East during World War 2 and had lived a portion of his subsequent adult life in Africa before returning to the UK with his wife to bring up his family in the suburban city home where he continued to live once his children grew up, and where his wife died.

Over recent years he had become increasingly frail however there was no starting point for this. His GP had believed his death had been imminent for the past few years. *'I'm surprised Mr Hughes is actually still alive.'* Discipline was very

important to him, forming the main thrust of our first interview and encompassing much of his identity.

Anna: 'what keeps you going?'

Mr Hughes: 'I've had to do that all my life, keep going. And well, discipline that's the centre of everything, discipline. You discipline yourself to do something every day and you do it, no messing about. If you start to slip, then you remember "discipline....you've lost the place" I'm a disciplined person.'

The modern world lacked discipline to Mr Hughes *'And they say "oh, I won't do that nowadays". No, they won't do anything nowadays. They want the money but not to work'*. He viewed those that he heard about in the media and those involved in running institutions and hospitals disparagingly, expressing how he could sort them out. *'They'd cry their eyes out if they ever get a manager like me in these places, cry their eyes out because they'll be on their way'*.

His experience of being a hospital inpatient was another source of his anger and he complained bitterly about the behaviour of the health care staff, again focusing on what he considered as laziness *'The doctors are not so bad when they're supposed to be busy but if you go along the corridor, you'll see six or seven of them sitting in there, sitting in one of the little bit of rooms in the back. What are they doing? – Nothing. Nothing. And it's the same with the nurses, you go along to the place where the nurses were and they were always sitting in there. Now, a bell went off and there was a fight about who was going to answer it. And I would ring the bell because somebody was... there was a man fell between the bath and the wall one night and, of course, he was stuck, he couldn't get out and I couldn't help him.'*⁷

He wished to live independently in his own home with the help of his daughter and gave no mention of any alternatives for the future. He railed against outsiders 'interfering' in his life and wished to be left alone. *'They've all been pushing me to get help, 'I think they are meddling too much'*.

⁷ Stories of neglectful or inadequate care by nursing staff aroused complicated emotions for me throughout the whole study. I struggled to understand how such poor practices could occur and how nurses could be so uncaring. I hoped that these events were unusual but they always infuriated me.

Mr Hughes had intermittently been admitted to hospital and prior to my meeting him, had been discharged with a package of care which he summarily dismissed on his return home blaming the lateness of the carers arrival in the mornings and his discomfort at having strangers in his home. However he was dismissive of any level of outside help even to the point of having a personal alarm.

Gillian: 'We were scared you were going to have a fall and not be able to get to the phone but you didn't want an alarm.'

Mr Hughes: 'Oh, I don't want an alarm. I've enough things round my neck without an alarm.'

*Gillian: 'He's refused that as well. He just won't accept any help, apart from me, so it's just muddle through and sort of do the best we can really.'*⁸

I began to see that having his daughter provide help for him allowed him to normalise his level of dependence. He could maintain his concept of himself in the manner that help from 'outsiders' would threaten because even although she spent the best part of each day with him he still insisted that he was managing on his own. Gillian also tended to interact on his behalf with health care professionals allowing Mr Hughes to further distance himself from his physical decline. Similarly the GP understood Mr Hughes need to believe in his own independence. *'He definitely wants to be in his own house. Em he likes to pretend that that means he's independent'*. This 'distancing' of his current self was evident in how he increasingly used 'you' to describe his situation. *'You've got no help with your hands, your hands are useless to you,'* or by removing the personal pronoun entirely *'It's just bones that have been stuck for a while'*. He was keen to tell me who he was and what he stood for, which was a moral self that was disciplined and busy, and in contrast to what I may assume from his outward appearance. I felt aware that Mr Hughes was presenting himself to me, this outsider, and gave little away that would betray this outward appearance.

⁸ I could not understand why Mr Hughes was so insistent on refusing personal help. I felt he was being so stubborn. This highlighted some of my biases and assumptions. If he was a younger man with cancer I may see it as 'fighting'. Again, it was easier for me to identify with Gillian therefore I had to make a conscious effort to try to counter this in my analysis.

That his physical decline did not mean the same thing to him as it did to others was highlighted by the GP. *'I mean he's gradually become more frail and less able. He doesn't really see that.'* What I believed was that he was not going to allow himself to resemble the 'weak willed' malingerer that he saw in the world outside.

Gillian: 'You're supposed to have your stick, aren't you? You're supposed to use your stick?'

Mr Hughes: 'Och, I know! I've got as many sticks and that but... There's people that don't need the sticks, you see them across there, walking along with a stick and then going back with it on their arm, you know.'

He was insistent that without a clear medical reason then he did not and would not require outside help. *Mr Hughes: 'Aye, I told them, I says "one of these days" I says "I might need you but not just now."*

Anna: 'OK. And if you look into the future at a time when you might need them, do you think about the future at all, how you would like things to go? I mean, you're saying "a time when you might need them", do you...?'

Mr Hughes: 'Uh-huh, ah well, if I get any worse, you know. If they cut my legs off or something like that, I'd need a wee bit of a help, uh-huh.'

Help should go to those that needed it which was not him. *'And that's what I was saying "go and look after the people that need more than I do"'*

Yet, that Mr Hughes was frustrated at his current situation and his inability to physically do the things that he wanted to do was expressed by all.

Mr Hughes: 'I've got terrible legs, that's the only thing, and feet, but otherwise I feel I want to go on a marathon or something! (do you!).'

Gillian: 'He gets frustrated.'

GP: 'he's annoyed with himself when he can't do what he would like to do so he's frustrated'

However he remained hopeful that he would improve primarily via physiotherapy sessions at the day hospital.

Mr Hughes: 'Well, they're trying at the moment to get my walking better, you know. But I feel a lot better, I feel a lot happier with that.'

Time point two:

I decided to return to Mr Hughes after 4 months as he was becoming weaker and experiencing increasing tiredness, instability and falls and worsening pain. He had also experienced a number of admissions to hospital, was again discharged with a package of care which, as before, he dismissed once back in his home. He was still angry and he continued to fight to maintain his sense of independence. There were some cracks beginning to show in his resolve, however as he now accepted that he needed help even though he continued to refuse.

Mr Hughes had recently fallen while in his garden where he remained stranded for two hours before he was noticed by a neighbour. His sense of security had been badly shaken so that he had accepted the personal alarm that had been resisted thus far.

Anna: 'so what made you change your mind about getting [the personal alarm] then?'

Mr Hughes: 'Why I've changed my mind? Just after that when I got caught in the garden [that time]. I had nobody, nobody to help me.'

However, he remained dismissive of it and kept it on his mantel piece in his living room. An important factor here was the 'visibility' of his frailty as he refused to wear this 'badge of dependence' around his neck. Similarly it now seemed clear that outside carers coming to his door each day would be another visible 'badge of dependence' to the world. If his daughter helped him, he could maintain the appearance, to himself and others, of coping and thus maintain his self-worth. I began also to understand his insistence on having his outer front door open on to the busy main road outside his house as a public demonstration of coping.

Both Mr Hughes and Gillian talked of his tiredness while Mr Hughes described its impact in terms of not being able to 'do' anymore. *'I get tired, but I think that's up here [points to head] I'm getting tired, seeing all the things I want to do and then I can't do that'*. Having lived his life as busy, being idle was anathema to him.

Gillian: 'Aye, you've always been busy, you don't like sitting down.'

Mr Hughes: 'Oh, always busy, uh-huh. There's not time in 24 hours to do too much.'

Gillian: 'If he sits down now he falls asleep so he doesn't like it even more so he tries to just keep going with things.'

Socially Mr Hughes still had an old friend that would visit every two weeks.

Mr Hughes: 'He comes in quite often, about every fortnight he'll come in (mm mhm), have a chat, different kettle of fish altogether. He knows what I'm talking about and I know what he's talking about' and felt that he could rely on his neighbour who he would chat to in the garden.

Mr Hughes: 'My neighbour is very good.'

Gillian: 'Yeah, he's got really good neighbours.'

Mr Hughes: 'Aye, if he sees you struggling he'll come over and help you without any askance or anything.'

However his sense of alienation from others in the broader world was felt as he struggled to make himself understood.

Mr Hughes: 'And that's the frustrating thing of course, when you're speaking to somebody you want to say something and you've got to think very, very quickly what you're putting to these people, your health or whatever you've been (mm mhm). Of course you make mistakes and you make mistakes in, in what you're saying and you know you can't take them back, you've said them, but that's a frustrating thing because you never know how these people are going to take it (mm mhm) and just you know if you're telling the truth or if you're not telling the truth. And there's so much of that around nowadays, I don't trust anybody'

Anna: 'So you don't get the time to think through what you want to say?'

Mr Hughes: 'Uh huh, that's right, but you don't get time, and especially on the phone they chatter like that on the phone and say oh, for heaven's sake, I say speak much slower and they can't.'

This second interview with Mr Hughes was cut short due to him becoming tired and consequently muddled in his conversation. I was therefore unsure whether to see him for a third time. I worried that he was beginning to decline cognitively and felt that to carry out a mental state test would insult him. However when I spoke to Gillian she told me how her father had explicitly asked for me to come back and see him and

suggested that we do separate interviews. I complied with their wishes and was prepared to not carry out the third interview if Mr Hughes was confused but to allow him the opportunity to speak to me as he wished.

Time point three:

On this occasion, however, Mr Hughes was alert throughout. I had initially felt pleased that he had asked to see me again and considered that I had been of some assistance to him or that he felt that he could confide in me. At this interview, however, he continued to tell me a socially acceptable interpretation of his experiences and I realised that what my presence allowed him was the comfort of self-presentation. Nevertheless, he now differed as his moral outrage had lifted and the long rants were absent. These were replaced by a resigned and flattened affect and occasions where his suffering was laid bare.

Mr Hughes: 'See, my feet's my problem at night.'

Anna: 'Is it hurting?'

Mr Hughes: 'Oh! Terrible, I've got to get up and walk the floor.'

Anna: 'Oh'!

Mr Hughes: 'But... if it would go away and stay away once I've done that but it doesn't, it comes back in⁹ about 20 minutes...'

Similarly Gillian was aware of the need to control her father's pain. *'I think just to get him release from that pain sometimes, would be good.'* Yet she explained the difficulty in doing this. *'You get into a vicious circle because, you know, he has got pain in his legs a lot of the time but to increase his painkillers now puts him at higher risk of falling.'* *'The GP said sort of previously, last year, that for her to up his pain relief it would have to be probably in hospital to see the effect it was going to have on him before they let him loose in his own house because he just can't risk any more falls.'*

⁹ I could not gain the GP's views on this as our interview had occurred prior to pain becoming a significant issue for him.

On putting this position to Mr Hughes it is clear that he would wish pain relief at any cost however.

Anna: 'How would you feel if the doctor said that you could try strong painkillers but you might have to be in hospital to see that it's OK and doesn't make you unsteady? How would you feel about that?'

Mr Hughes: 'I don't mind if they take away that pain. The pain, just the pain in my legs and that, I don't mind.'

His social world had diminished towards the end of his life as his final friend became too unwell to visit. *'Aye, but these people are all away. That's what's wrong to me, no matter where I've been; now I've got to this age all my friends are away, there's none left.'* He was now unable to hold meaningful relationships other than with his daughter and indeed he did not think that younger people understood him as their worlds were poles apart. *'But it's children now, they say 'whatever' but I don't know what's in their mind at all....I don't know. But you could enjoy a wee chat with somebody on more or less the same level as yourself that's been around and can talk about these things. But you talk to youngsters like that and they just walk away, they just don't want to listen. They don't want to know, don't want to know.'* There were attempts to connect Mr Hughes to other older people, who may have been able to understand him in a way that he felt younger generations could not, by a trial visit to a day centre. However this was unsuccessful, he refused to return and described feeling distanced from the other older people there. *'We never went back up there, aye. They sit and watch television and I don't like television.'*

In contrast, Gillian described how her father had enjoyed an interaction with a young man that had visited and they had talked about Africa, revealing that what he desired was a point of commonality. Similarly Mr Hughes had previously described enjoying visiting the Day Hospital and had talked about others there by employing a collective pronoun: *'but up in that other place you were never off your feet (Uh-huh) I mean, you're not sitting ten minutes, a quarter of an hour and somebody else wants you, you know, and pummels you around and all that.'* The day hospital suited his world view as he felt busy there; there was a purpose to going. It offered hope of improvement via the physiotherapy that he had greatly valued. *'[Day Hospital*

physiotherapy] made a big difference but, as I say, when you get along... [sigh]... you're so relieved to be getting something done that you start to do it yourself'. However discharge from the day hospital also meant that he lost any real hope of physical improvement.

Mr Hughes' relationship with his daughter was now strained to the point of acrimony as she felt that she could no longer manage his demands on her. *'He dominates my life. You know, he says "jumper", you know, "I've fallen" and everything has to be dropped, I'm the only one that can sort of want to sort him out.'* Gillian at this stage began to resist her father's demands *'And I'm starting to be a wee bit firmer with him that there's some things that I'm just not going to do.'* He was described by her as having become confrontational and paranoid *'He goes through wee spells where... you know, this week he's been fine, he's been quite placid and... but then he'll suddenly hit something and he'll turn quite nasty.'* Gillian was duly stung in response, *'and then I just... I was getting mad at him, I thought "I'm not being accused of stealing" you know, I do everything for him.'*

Mr Hughes' sense of place in the world was lost as he expressed feeling apart from other people. *'That's you, you're going over a wall or somewhere and they're on the other side.'* He had become restricted to the indoor world engendering a feeling of being imprisoned, *'and you see I'm in a cage and I can't get out.'* The loss of simple acts such as going out in the garden were keenly felt as they had allowed him to connect with the world and with his neighbours. He also felt that people were avoiding him now because they considered him infectious. *'Well, people are hesitant now, I think. I think they're not sure what you've got, are we going to get it in the family and this sort of thing, I'm sure that's the feeling they've got.'* However Gillian described her father as reluctant to leave his house because of a sense of shame over his current physical situation, *'and I said to him "you know, if you get a wheelchair I'll take you down to Tesco and I'll take you out" "I'm not going in one of them, I'm not letting people see me in a wheelchair" so there's the pride bit as well. And I think with staying on the main road, you know, it is quite, erm.....quite a lot of people see you and things.'*

Although at the start of the study Mr Hughes described his daughter as his girl Friday over the course of the interviews Mr Hughes expressed the sense that relying on his daughter was unfair. *'It's taking their life away from them, that's not good, it's not a good feeling.'* The notion that Gillian was burdened was felt by their shared GP. *'I feel it's unreasonable that his daughter should be expected to continue with this for some unforeseeable time. And I think perhaps she did anticipate that this was going to be for a much shorter time and she's now got herself into this, very hard to extricate yourself you know from something that seems to be working, it's working for him.'* The GP was highly regarded by both Gillian and her father. However, as the family doctor to both Mr Hughes and Gillian, he was required to consider and balance the needs of both. *'I sometimes worry about her because she does so much, she's torn between her three children, her husband and her father'*. Certainly the GP felt that Mr Hughes was surviving well beyond her expectations and felt that he should have accepted outside help rather than lean so heavily on his daughter.

Anna: 'So if you were to say that one main difficulty, one main, what is his main problem do you think?'

GP: 'Stubbornness. Refusal to accept help from outsiders I would say (okay).'

The GP's support encouraged Gillian to begin to resist some of her father's demands and she describes the GP as making the ultimate decision to arrange carers. *'Everything was a struggle, he couldn't get dressed, you know, and the doctor said to him "right, you know, there's no option, you're getting carers whether you like it or not" so she arranged for them to come.'* Gillian's increasing resistance coincided with Mr Hughes building sense of guilt in burdening her yet without his daughter's continuing complicity Mr Hughes could no longer maintain his belief that he was 'coping'. He had now accepted outside carers and also now wore his personal alarm in the form of a new device that bypassed the issue of public perceptions by resembling a watch as Gillian said. *'Even when he was out in the garden he wore [the personal alarm] there. Because it looks more like a watch, if somebody's looking from a distance, rather than it dangling round his neck so...'* However Mr Hughes described the decision to wear the alarm as very much an active one made in response to his recent circumstances rather than something that had been imposed upon him. *'Well I had to do something.'*

Unfortunately, for Mr Hughes these steps involved admitting to himself that he needed outside help. This forced him to relinquish the very essence of who he was and how he had understood his life as avoiding failure by self-discipline. His story had no clear beginning or cause and as his suffering increased so did his anguish as to why. I had understood from the start how much Mr Hughes believed that the will of the mind could conquer the body. Accordingly, having no clear causative pathology to which he could attribute his bodily failings, his only option was internal self-blame and so he searched for a cause. He considered undiagnosed viruses contracted years ago in Africa, and that doctors knew what was wrong yet kept it from him. *'He was on yesterday [to] the doctor, he hasn't... he said "what's actually wrong with me?" I said "it's old age" I said "and your heart's not working properly" – "no, it's not that" he said "it's something, it's sclerosis or something, it's... I think multiple sclerosis, I'm not sure" and then he said "it's the worst one possible that you could have and I know that, that that's what it is but she's not telling me that, you're not telling me that" and I said "because that's not the case.'*

Mr Hughes did not understand what was happening to him and wrestled with an internal battle to remain true to the values of discipline and independence that he had held throughout his life. Having previously expressed defiance in the face of his difficulties Mr Hughes final interview described feeling trapped frustrated and hopeless.

Mr Hughes: 'And you see, I'm in a cage and I can't get out.'

Anna: 'Oh dear'.

Mr Hughes 'Aye, but years and years now. Oh, it's frustrating I suppose, it's worse than ever.'

Death now seemed to loom for Mr Hughes and that he was still alive was a surprise to both Gillian and the family GP.

'He has definitely been on a slippery slope and he seems to do that for a wee while and then you think "oh, here we go" and then he'll suddenly sort of plateau again and he can be OK like that for a wee while and then he'll suddenly slide again'

Considering the future, Mr Hughes was contradictory, offering me occasional hopeful statements, however he was more negative describing a futile existence: *'you say to yourself "well is it worth it, all this nonsense?"'*. By now Mr Hughes felt his life was intolerable.

Anna: 'Do you find it hard to keep going, ever?'

Mr Hughes: 'You feel you want to walk out there and walk under a bus.'

Anna: 'Oh! Oh dear.'

Mr Hughes: 'You just get so... I get so frustrated now, you get angry...'

Gillian repeatedly told me how her father had had enough of existence. *'I mean he will come out with things at times, you know "I've had enough" you know'*.

Five months after last seeing Mr Hughes Gillian called to tell me that he had died. She recounted that he had continued to suffer from the pain in his feet which had made resting intolerable. He was found dead on the floor of his home.

5.2.1 Concluding Mr Hughes' Story

Ultimately Mr Hughes accepted outside help but in doing so gave up on his insistence that he could discipline himself into his much prized independence. It was a shameful situation in his eyes as he regarded those that could not discipline themselves as being weak or lazy yet there he was, and without a medical explanation to externalise the responsibility. This was a profound loss for him because it was such an integral aspect to who he was. It was important on an existential level giving him meaning and purpose throughout his life. Since he could no longer 'will' himself as he had always believed he could, he was left wondering 'why' he was the way he was and searching for an explanation which he believed was undiagnosed by doctors or that they were hiding it from him. In addition, he lost the regular contact with his only contemporary friend and had tried and rejected the only other potential source of relatable company at the Day Centre. He thus experienced total isolation and alienation from the social world and felt that he no longer belonged, while at the same time rejecting it from his own life. His story was of a struggle to maintain his independence, to be losing that struggle and begin to

give up, with a final intolerable assault being on-going physical pain. He gradually gave up fighting and gave up living, dying a few months after our final interview.

Gillian: 'I think he only sees [having outside help] maybe as giving in...'

5.3 Mrs Gray

'It's... it's not life, just an existence. And I suppose lots of people must feel that way at my age but I can't accept it, I don't know why but I can't accept it. I just always want something to be happening'

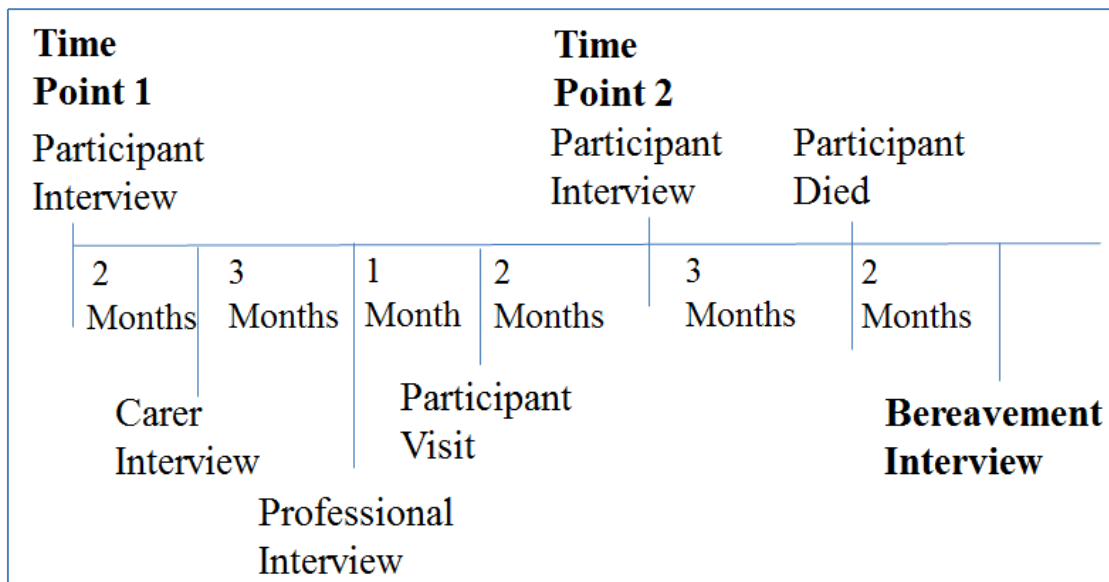


Figure 11. Time line for Mrs Gray

Mrs Gray completed two interviews with me although I met with her on another occasion during one of her hospital stays. I also carried out two interviews with her daughter Alison, one a few weeks after Mrs Gray's first interview and the other after her death. Mrs Gray had nominated her home carer for a professional interview which I carried out in the carer's home. Mrs Gray lived in a cottage in a small village having moved from a larger family home in a nearby town a few years ago. She had separated from her husband when her daughters were young, having no contact with him since, maintaining employment and bringing up her family on her own.

Time point one:

Mrs Gray had experienced multiple hospital admissions over recent years but was in a period of stability when we first met. Home carers visited daily to help her dress, to prepare meals and to help her to bed. She now struggled to mobilise with her walking frame and spent her days, and some nights, in her living room armchair surrounded

by books and scattered newspapers. Mrs Gray had a very close relationship with her two daughters, one in particular (Alison) whom she nominated as an informal carer, and saw them regularly. She also talked of neighbours and about her close bond with Katy, one of her home carers who saw her most often. This young woman was described as being understanding and respectful to her and like a friend. *'I must say the carer that I have Monday to Friday is first class (mm hm) and she is good with me (mm hm) and she respects me and I respect her and I'm very fond of her.'* The regard was reciprocated by Katy who spoke fondly and respectfully of Mrs Gray in return endeavouring to care for her in a manner that went beyond purely physical tasks *'I mean, one of the reasons [Mrs Gray] likes... she says that she likes me and respects me is that I do understand and I listen and I don't mollycoddle her into thinking... you know, I don't treat her like she's stupid, I don't turn round and go "oh, come on, we can go and do things" you know, and come up with things that just aren't going to happen. I just... you know, I just try and comfort her more than anything rather than sort of tell her "oh, it'll be alright", I just sort of comfort her and go "oh, come on [Mrs Gray], it's not all that bad, you know, you get to see me every morning!" (laughs) things like that, you know "we're good friends, aren't we!" you know "at least I get to come and visit you".* In contrast Mrs Gray described the attitude of the other carers that visited her *'some of the others [carers] barely talk to you they just, you're a job, you're a number to them.'* Such concerns were similarly raised by both Katy *'I get very angry with other carers not doing enough and, you know, it's like "well, I've got time to do all that, why don't they have time to do all that?" and you know... so you feel like you're sort of fighting against other people as well to make sure this one person is sort of cared for properly,'* and by Alison, who described carers as a source of despair *'some of them I just despair there's no other way I can describe it I just despair and I think I wonder if you treat your mother like that, I wonder if you'd speak to your mother like that you know' 'sometimes patronising, sometimes dismissive, I'm listening but I'm not listening'.*

To Alison, there was a general lack of respect for her mother from all professional quarters and she was vociferous in her accusations of ageism in hospitals

highlighting an interaction with a physiotherapist as an example: *'there was one time the senior physiotherapist came into the room at the [hospital] and started talking over to her to me and I said excuse me my mum's in the bed it's her you talk to. I'm listening OK you talk to her not over her to me and she didn't think there was anything wrong with that.'* Such ageism was clearly felt by Mrs Gray who felt there was a poor regard for older people generally: *'sometimes I think that what [older people] say isn't of great importance'* and the lack of common courtesy by those she came across: *'and I think when you get older you become a little more sensitive and it's nice if somebody passes the time of day with you or speaks to you'*

Mrs Gray was keen to tell me about her life and who she was, stressing how she had always enjoyed history and politics and lively debate. She kept up with these passions by reading books and newspapers, watching television programmes and imparting her knowledge to her grandchildren. She talked of herself as assertive and was at pains to describe how she could still stand up for herself as having *'all her marbles'* citing the views of others to legitimise this. She seemed keen to tell me who she was in contrast to what I may have seen before me. Mrs Gray visited a Day Centre yet expressed her frustration at the limited activities available there. *'You've not got very much imagination, you're quite happy for us to do exercises in the morning and to do something like bingo in the afternoon, could we not have a discussion about something or could we not go someplace, even if it was just on a bus run'*. She expressed her sense of boredom: *'you get bored sometime but then I'm on my own quite a bit so I've had to content myself'* which was elaborated on by Katy. *'She's not physically getting stimulated and she's not mentally getting stimulated either and I think that's a big issue... and with a lot of older people as well, not just [Mrs Gray]'* She was striving to stay in control of her world as her physical self was increasingly relinquished to the control and care of others. However, even her designated visits to the day hospital threatened her sense of control as she feared that she would be kept in hospital following a visit as had happened in the past.

Mrs Gray: 'I always think [that I'll be kept in hospital]. But I just wouldn't stay. I don't suppose I'd have much option but I'd have a damned good try.'

Anna: 'So is that the thing that worries you most about going to the [day hospital]?' 'Yes it does. It's in case they keep me in.' Mrs Gray's daughter highlighted the issue also. 'She doesn't want to be [in hospital] I think the older and the longer she stays out of hospital she feels the next time she goes in she's never going to get out.' Here there was an aspect of loss of freedom as highlighted by Mrs Gray's choice of wording to describe permanent institutional residency. *'My daughters fought to get me home; the doctor there said no, I had to go into a nursing home or a hospital where they looked after me all the time'. 'I'm not an inmate'*

Physically, pain and lack of mobility were recognised as major and increasing problems for Mrs Gray. She was treated with opiate medication for her pain and although Alison was concerned over the confusion that it could induce and the dependency that resulted she described her mother as continuing to take it. Attempts were made to increase her strength and mobility via physiotherapy at the Day Hospital, where she feared to visit and would, Katy told me, find every excuse to avoid. In addition the home care staff had been given instructions to continue to encourage exercise at home, yet Katy explained the difficulty in helping Mrs Gray to mobilise at home and her frustration that her efforts were futile as other staff simply did not try. *'I make her do [exercises] anyway but the other girls, because they're not in there Monday to Friday, they're not regular, they just go "OK, you don't want to do it, you don't do it" you know. But then a lot of... especially the weekend carers, they just don't bother, they're just like wanting out as quickly as they can anyway so one less job for them to do, it's like "whey-hey!" Whereas, you know, for me – well, I wouldn't do it anyway – but I wouldn't have the luxury of doing that, it's... her health needs to be improved'.*

Although Mrs Gray mentioned her depression, Alison described it as a lifelong problem while Katy considered it as Mrs Gray's most significant difficulty. *'I feel it's the depression that's beating her, she needs lifting up, she needs motivation, she needs something to look forward to.'* Katy described Mrs Gray's feelings of loss of control: *'and I think she... that's the worst part, she's lost all control over everything, everybody else is telling her when and what she's to do, you know. Even*

down to getting up in the morning, she's got to get up when the carer comes; she's got no choice in that'. Katy also described a loss of dignity resulting from an increasingly physically frail body: 'And the worse she gets physically the worse she will get depressed because she's losing a little bit more dignity each and every time, you know. I had to start, you know, helping her with the toilet and things and she's always "oh, I'm so sorry, I'm so sorry!" I'll say "oh, don't be daft, this is my job!"

Although Alison and Katy described generally a much more negative picture of suffering this was further complicated by Mrs Gray's fear of dying. *Alison: 'I said to her last week she said she was just tired and that, I said are you tired of living, she said basically yes, I said but you're scared of dying right, she said yes.'* This fear of dying contrasted with an exhaustion of living and this suffering was also described by Katy. *'I've got to hear this lady going on that she just wants to die or crying because she hasn't got to sleep all night because she was frightened she would never wake up and... (sigh) it's, erm... it's difficult, it really is difficult for her.'* In considering the end-of-life, Alison had talked with her mother about her wishes which focused on remaining in her own home. This was something that Alison felt secure that she could aid her mother in achieving.

Anna: 'so you've have you talked with her then about staying at home and that's what she wants and?'

Alison: 'that's absolutely what she wants; she wants to die at home'

Anna: 'ok'

Alison: 'and I promised her that's exactly what will happen'

However, in speaking to Mrs Gray it was clear to me that such conversations did not mean that Mrs Gray was considering her death as imminent. *'I want to be here [alive] for as long as possible'*. Interestingly, Mrs Gray offered a potentially more practised and publically acceptable view point at our first interview yet essentially described the essence of what kept her going: *'As long as I've got the health and strength to enjoy my television enjoy my books and listen to debates that I can still understand and enjoy and as long as I see my family that's me, I'm contented with that'* and retained some hope for the future: *'That's the one thing I would like is to be able to go out now and again'*

I tried to stay in contact with Mrs Gray eventually finding that she had once more entered a period of repeated hospital admissions. After numerous attempts to see her in hospital to find she had been sent home again, I was finally able to visit her in a hospital ward. I found her lying peacefully in a cloud of bedding too sleepy to undertake an interview. Instead she took my hand and asked me to stay to talk to her. We talked for about 45 minutes as she spoke fondly of Katy and her beloved daughters, reiterating her hope of getting home soon. Although she did go home again, it was short lived. Alison had taken time off work to stay with and care for her mother as she felt her death was imminent. Unfortunately Mrs Gray had retained her fear of dying to a degree that no amount of support from Alison made it manageable to remain in her home¹⁰.

Alison: 'about nine o'clock we got her into bed. By half past ten I had her out of bed and in the living room because she was screaming "don't leave me, don't leave...!" I couldn't even go to the toilet, when I went to go to the toilet she was screaming. So her and I sat up all night, me in one chair and her in the other. And it was "this is some way to die, this is some way to die"'

Thus Mrs Gray's daughter described her mother's GP as taking the decision to readmit her hospital, which was where I met her for the last time.

Time point two:

I found Mrs Gray sitting in the hospital chair by her bed and her demeanour was markedly changed. Her affect was flat, her head hung and she rarely looked at me as she spoke. She no longer told me of her real self that was intellectual and assertive and 'had all her marbles,' but rather seemed resigned with being what she now appeared to be. She was not fighting anymore and spoke with none of her previous resistance. When I took her hand she stroked it gently and then let it drop lethargically. She was becoming increasingly tired 'But I just... I always so tired just now' and now suffered from unbearable pain. '...and it just... I don't know what it

¹⁰ This is not implying a criticism of Alison who described her anguish over the episode and did everything she could to assist her mother in her quest to stay at home.

was, I was in agony and I was most uncomfortable, I just felt I wasn't going to see the night through and it's a horrible feeling.'

The ward was a care of the elderly unit and the charge nurse told me that Mrs Gray was aware that she was awaiting a place on a long stay unit. Mrs Gray's desire to go home was stated repeatedly throughout the interview although compared to the insistence of before this was expressed now in a futile and whimsical manner as if she did not realistically believe what she was saying. Instead her words conveyed a longing to escape. *'I'm hoping that my daughter will come today and she'll take me either out of here or take me home.'* Perhaps voicing the reality was too painful as her daughter explained to me that she was fully aware that she would not be going home.

Anna: 'did she know when she went back into hospital that time that she was not going to perhaps get back home?'

Alison: 'I had to be straight with her at that point.'

Anna: 'mm hm'

Alison: 'I didn't say immediately, it was the second week when she was stabilised and that, she was talking about going home and I said "mum, that's not going to happen but I'll tell you what is happening" – because I had this great big debate about where she should go and eventually [consultant] agreed that she was a candidate for [long stay hospital] – so I said "you're going to go to [long stay hospital]" I said "now, you don't have to, you can say you don't want to go" I said "but you're going to go there as a boarder for a wee while to see how you are and if things work out, fine, you can go home, if they don't you're in [long stay hospital], you'll no longer be a boarder" and I explained the whole process. So she was quite happy with that. She never made it to [long stay hospital].'

Mrs Gray was resigned that, for the sake of others, she may not be able to go home even although it remained her dearest wish. *'The idea [of a care home] doesn't appeal to me but I feel, in fairness to other people.....'* However moving to a care home or long stay unit was at least moving forward. *'I don't feel particularly happy about it but I feel it would be something definite in the right step.'* Mrs Gray struggled with the uncertainty of her future and was distressed that her life was

‘stagnating’ as she sat on the hospital ward week after week. *‘Right now I just feel everything’s at sixes and sevens and I feel I’m not getting anywhere or doing anything.’* Her wish to gain some control in her life repeated throughout. *‘I think it’s always because I’ve been very much master of my own fate.’*

Mrs Gray’s sense of who she was faded in the chaos as she lost control of her life and weariness overtook her motivation to continue the activities that were important to who she was.

Mrs Gray: ‘usually I have newspapers but I don’t know what’s happened to them. And I seem to have lost interest in reading...’

Anna: ‘And that’s not like you, is it?’

Mrs Gray: ‘...which is not like me.’

Anna: ‘No.’

Mrs Gray: ‘I’m an avid reader, always have been.’

Anna: ‘Your politics and history and...’

Mrs Gray: ‘Yes. But I just have no interest in anything at the moment.’

Mrs Gray now clung to her daughters as the last vestige of what made life meaningful.

‘My two daughters just mean the absolute world to me...(I know).....always have done. And life without them is nothing at all.’ Certainly her social world had shrunk to encompass her daughters only, since the carer that she was so close to had inexplicably been removed from her care.

To stay in her own home was of fundamental importance to Mrs Gray as this was where she could follow her interests and retain a vestige of control in her own life. *‘I think I’ve got this idea that if I was at home things mightn’t always be smooth and that but at least I’d be in my own home and I’d be in control of things, whereas now I just feel I’m an onlooker.’*

‘It’s so regimented, you know, you feel you’re under somebody’s finger the whole time and it’s just not what I want.’

Having previously voiced her desire to keep living she now saw her life as futile. *'It's... it's not life, just an existence. And I suppose lots of people must feel that way at my age but I can't accept it, I don't know why but I can't accept it. I just always want something to be happening.'* Mrs Gray no longer offered any sense of hope but talked longingly of her wish to remain engaged in the world in contrast to the life she now had. *'It was a case [that others regarded her as] "well, you've reached an age where things'll not happen now, you'll have to just take things as they come and take it easy" – I wasn't ready for that. That sounds selfish, I know, but I just wasn't ready for that kind of life and I still don't feel ready for it.'* *'I just want to be normal and to see people and have them visit me and to be able to go out in my wheelchair once in a while and talk to people.'* She now seemed aware that death was imminent voicing how she wanted her life to end, but on her own terms *'I want to go home. And I don't want to be a nuisance, I just want to be there in the background, have my cup of tea and whatever it is that's going and just let my life drift that way.'* *'I don't want to have time drag on or draw out but I'd like [pause]... as I say, I'd like to feel I'm more in control'*

Bereavement Interview:

Mrs Gray never left the ward remaining there and dying three months after I saw her. I was, however, able to piece together the story of her death in a bereavement interview with her daughter. Mrs Gray's condition continued to deteriorate on the hospital ward and she became weaker and very distressed. Alison asked for sedation for her mother due to her levels of distress however felt that the staff were unwilling to take this step.

Alison: 'I was pretty concerned, as was my sister, at the just total lack of appreciation of.....people not understanding the difference between being in psychological distress and pain relief and thinking if you gave pain relief that was the main thing'

Alison was distressed by her mother's death citing unmet needs in terms of psychological distress and spirituality. Again, though, her daughter describes staff in the hospital as having not managed her mother's spirituality in that the religious

artefacts that were of such importance to her were regularly tidied away and put out of sight.¹¹ Similarly, the newspapers that were brought in for her mother to read and formed such a part of her sense of who she was were also tidied away and unavailable to her.

*Alison: 'I took her all the different types of things that she liked, a drink – they buried them, you know? Took her in books, magazines, read the newspaper to her every day, if she didn't feel fit to read it I would read it to her, you know.'*¹²

In fact Alison went as far as to claim that the ward staff simply did not understand the needs of the dying and that they did not deal with spirituality appropriately.

'I think for the staff to be a bit more respectful of her position, of dying, to be a lot more aware of the process of dying and the stages and needs that people – which vary according to individuals – have in their lives about dying.'

'What I do expect [nursing staff to do] is to respect that whatever artefacts or symbols of her religion, she has them close to hand with her, you know? And I don't think there was much, if any, respect for her spiritual care at all.'

Alison believed that the overall standard of care for her mother and in hospital in general had been terrible *'And sometimes, I've got to say, in very undignified positions. I went in one day and she was sitting with an underskirt on, a dressing gown wide open, the blanket on the floor, her legs wide open. Totally undignified.'*

Furthermore she felt that her mother's suffering had been unnecessarily prolonged by being given intravenous fluids to treat a degree of renal failure extending her life for a further week. *'She was really, really poorly and they put a drip up on her, because you know, she was in chronic kidney failure, they put a drip up on her and by the*

¹¹ Interestingly, Mrs Gray never at any time told me about her faith and even having been in her home, there was no hint to her being a devout Roman Catholic yet once in hospital the importance of her religion came to the fore. Despite never mentioning my own ideals or considering them relevant, I have to consider that my own secularity meant that I did not pick up on cues about religion or implicitly did not encourage Mrs Gray to openly discuss these issues.

¹² Without having got to know Mrs Gray it would have been hard to appreciate the importance of having newspapers available to her or providing access to TV or radio to allow her to remain mentally stimulated in the manner that she had always chosen.

Wednesday she's improved. So that was at the point where my sister and I said "right", we're going to have this again, you know, you'll stick a drip up on her again and she's obviously responded so if she responds again but she's still got all this level of distress, at what point are you going to decide.....are you just going to let her die peacefully, you know?"'

Towards the end of her life it seems that Mrs Gray' physical pain was controlled however she remained tremendously distressed by her fear of dying which did not leave her until her very last days. *'It was only in the last few days she went to bed, she refused to go to bed, she was being nursed in the chair. She thought she was going to die in bed, that's why she wouldn't go. As soon as you got her into bed she was screaming to get out of it. And of course, she was banging her head off the cot rails' 'I mean, it just was awful to watch her banging her head off the chair and it was this "oh, oh, I don't want to die, I don't want to die, I don't want to die..."'*

Thankfully in her very last days Mrs Gray managed to make peace with what ailed her and to accept her death finally allowing herself to go to the place where people die, to go to bed.

'I said "how about we get the priest in and you have the last rites and you make a confession, I know you've done it but you might feel better if you do it again?" So she said "yeah" so the priest came in and he's heard her confession, gave her the last rites and she seemed to be a lot more at peace, a LOT more at peace. And throughout that week she just seemed to have come to terms with whatever was ailing her, psychologically that is, being peaceful and by the Thursday she was in bed.'

Sedation was then requested by the family and finally granted.

Alison: 'I'd to ask the nursing staff to give her something and they came in and they turned, and I was there with them, they said to her "would you like...?" and I looked and I thought "would you like...?" – She's supposed to get it, you know. Anyway, she said "no", I said "Mum, what the nurses are offering" – because the nurses weren't explaining themselves properly – I said "Mum, what the nurses are offering

you is some sedation” and I explained and she said “that would be really nice, that’s very kind of you, nurse.” And the nurse got quite upset, visibly upset.’

Anna: ‘Because...?’

Alison: ‘Because I think my mum was actually like saying to her “you know, I am distressed, I would like something” you know.’

Anna: ‘Mm-hm.’

Alison: ‘So she gave it to her and I sat and I stroked her hair and that and she says to me... the last words that she said to me, she said “you have been absolutely wonderful” and I said “well, you’ve been a tough old bird to look after, I can tell you” you know, and she just smiled and that was the first time she’d smiled in months. So she eventually fell asleep with me stroking her hair.’

Mrs Gray died three days after taking to her bed.

5.3.1 Concluding Mrs Gray’s story

For Mrs Gray, her home represented the place where she could retain some level of control in her life and where she could still be her. Home was where her books were, where she could watch political and historical television programmes and where she could maintain her connections to the world. Mrs Gray did not want to be tidied away like her books, newspapers and religious artefacts; she wanted to remain involved in and relevant to the world until her death. Remaining in hospital, unable to walk out, and with no end in sight was an intolerable existence so she gave up striving for what she wanted. However once she was able to find some peace with dying her story could finally end and she was able to briefly brighten before death.

Alison: ‘she wanted to be at home, you know, she just didn’t want to die.’

5.4 Bringing the stories together

Mrs Howie, Mr Hughes and Mrs Gray all experienced a significant physical decline which set off a chain of subsequent events impacting the other dimensions of their lives. They lost the capacity to control their worlds physically as their functional ability decreased. Unable to use the body they emphasised the power of the voice. Each held a single factor of deep importance that they were insistent that they would not give up. Mrs Gray wanted to stay in her own home and to die there, Mrs Howie did not want to go into a nursing home and Mr Hughes did not want day-to-day help from anyone other than his daughter. Each of these factors was rooted in deeply held personal values and reflected the self-concept of each person.

While they had the support of their daughters, their voices could remain powerful enough to avoid their fears but as the daughters became increasingly unable to assist their older relative in maintaining their position, the old person's voice became useless. They then had no option but to concede to not going home, to going into a nursing home, to accepting outside help. Once the body becomes unable to exert control over what happens one can retreat into the use of the mind and express self-determination through the voice. However, once this too is lost in its capacity to control or influence events, then one can only conclude that the self is useless. At our initial interviews Mrs Gray and Mr Hughes told me of who they were in contrast to what they may outwardly appear while Mrs Howie engaged with me in a manner that pulled us socially together, again revealing to me the perceived real self. In contrast the selves that were latterly reflected back to these older people by their new circumstances were not compatible with their own understanding of what a valued self was. Existing in severely restricted social worlds they were unable to reconstruct their sense of self in light of their new circumstances. Surrendering their final struggle represented an unbearable existential loss. They were forced to live their lives in a way that meant they must relinquish their life long sense of who they were and which gave their lives meaning and purpose leading ultimately to existential fatigue. These older people realised that where they now were was their story. All other possible futures were necessarily discarded. This was the future of their story

and it stretched out before them as an intolerable endlessness as summed up by Mrs Gray's home carer.

Katy: 'I think that, a lot of [the people that I visit], that's what they're finding difficult, it's they don't know when it's going to end. I mean, that's... as well, it's an unexpected thing, they could go on... they could go on for years and years and years being as ill as they are, being, you know... just gradually getting worse but it could last forever.'

Each participant then 'gave up' as Seale points out, 'human agency plays a part in deciding whether to enter the dying role' (Seale, 1998: 48). Their existential death was the final loss after which they simply waited until death of the body closed their story.

Broadly, then these stories tell of physical and functional decline, involving worsening of symptoms such as pain, instability and fatigue and regular emergency hospital admissions occurred gradually although steepening towards death. Social losses mirrored physical decline. Psychological suffering in the form of depressive symptoms and anxiety was closely followed by existential suffering. Their stories suggest that their experiences may echo a particular dying trajectory of multidimensional change for frail older people with rapidly declining physical capacity before the end of life.

5.4.1 Narratives at the personal level: Loss of self

Loss of self has been described by Charmaz in those with chronic illness. She details the conditions of living a restricted life, existing in social isolation, experiencing discredited definitions of self and becoming a burden as the factors that contribute to the suffering that leads to a loss of self (Charmaz, 1983; Charmaz, 1995). Each of these conditions existed for the frail older people described, in the months before they died. They all became severely restricted by their physically failing bodies and the living arrangements that they found themselves in. Their narratives all describe

moments of being discredited, via not being able to make themselves understood to younger people who did not take time to listen, being talked over by health care professionals to their physical needs being provided for while they themselves were disregarded. They all experienced social losses which in turn limited opportunities to reconstruct a valued self and they all, to varying degrees became a 'burden' to their loved ones. By a burden I mean that their capacity to engage in any degree of reciprocity diminished while at the same time their needs increased.

Charmaz further outlines how those with chronic illness can regard 'maintaining a normal life or returning to one' as symbolic of a valued self. Each of these three participants held their own version of normality. 'As long as an individual feels that he or she exercises choice in valued activities and some freedom of action to pursue these choices, everyday life does not seem so restrictive, suffering is reduced and self-images maintained' (Charmaz, 1995). Such loss of freedom was acute for Mrs Howie and Mrs Gray as their final destinations were, in essence, prisons. Unable to mobilise alone; they had no physical capacity to leave. Similarly Mr Hughes' use of 'trapped', 'stuck' and 'can't get out' reflected an alternative imprisonment. Once in their perceived prisons, apathy permeated their lives and each 'withdrew into suffering' (Charmaz, 1995). These participants thus lost all control of their lives and consequently their sense of where they belonged in the world. In doing so they were unable to continue their lives in a way that was true to whom they felt they were resonating with Charmaz's description of the loss of preferred identities in adapting to chronic illness (Charmaz, 1983). Their disability took on a master status as a dominant stigmatised identity. This became predominantly who they were. They were visibly physically changed, the 'inner self' could no longer override, and they were unable to reconstruct new identity goals and normal lives.

5.4.2 Narratives at the societal level: A battle

At the broader societal level these are regressive or tragic 'core' narratives of a battle fought and a battle lost (Bury, 2001). They evoked a particular societal narrative of the courageous battle against ill health and potentially feared end point, however

without the heroic undertones of a cancer sufferer. However such battles are publically located and socially supported. If those closest no longer support the battle then can it be maintained? Each of these participants was forced to concede to what they had struggled to avoid. Although the responsibility for making the decision for each older person to enter this final stage was attributed to a doctor there was a crucial tipping point. Each of the daughters in these cases had reached the moment where their resources to cope with what they faced were exhausted or simply unavailable. It was then the older person could no longer sustain their position. Mrs Howie's daughter told of their struggle with the burden of responsibility, of the ever present uncertainty of being 'on call'. Mrs Gray's daughter had no means to manage her mother's psychological distress while Mr Hughes' daughter could not sustain the ever increasing volume of practical daily tasks. The accounts illustrate how once the battle was lost then there was no way to reconstruct the narratives and the older person was left desolate, facing an untold and undefined future. Yet once it became clear to them that their death was imminent and the stories could end, then both Mrs Gray and Mrs Howie seemed to rekindle the light of their old self momentarily, and perhaps briefly reconstruct the self before their lives were finally gone. Whether this rekindling happened for Mr Hughes, I cannot say for sure but I suspect not.

In the end these frail older people experienced grand losses and many deaths, the social, the self and the existential before they died physically.

Chapter 6: Stable narrative - Stories of holding on to the self

Having explained how some participants reached the end of life having lost their sense of self, I will now describe how some of the other older people in the study managed to maintain a strong sense of identity and reconstruct their narratives in the face of their changing circumstances. These participants were Mrs Andrew, Mrs Ritchie, Mrs Wood, Miss Pegg and Mrs Baxter.

6.1 Mrs Andrew

'I'm not saying anything because I don't want to know! The last thing I want to know about is medicine'.

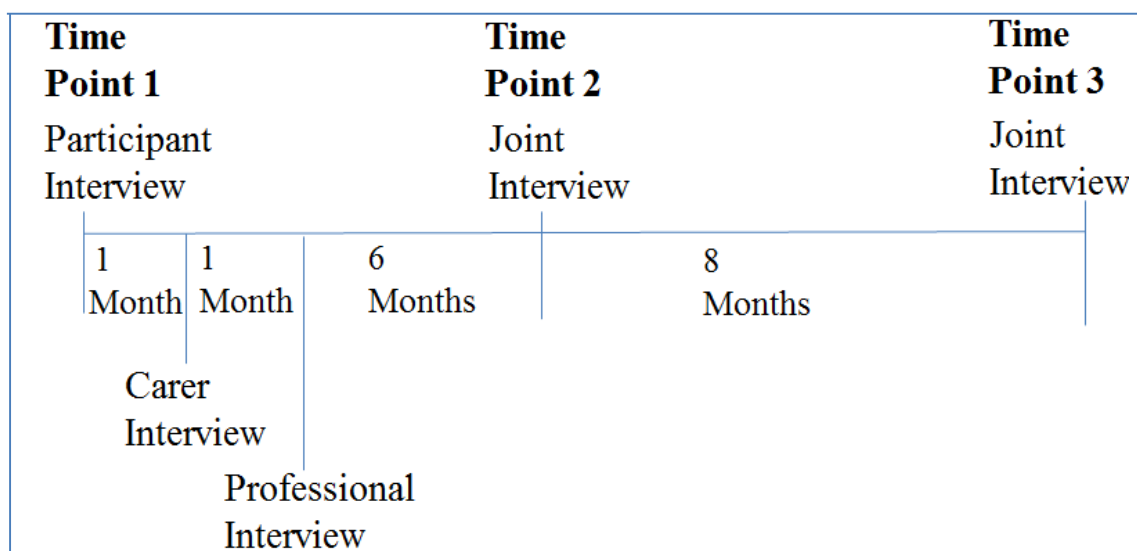


Figure 12. Time line for Mrs Andrew

Mrs Andrew lived with her daughter, Elizabeth, and her son who had returned to live with them following a marriage breakdown. The first interview with Mrs Andrew was carried out at the day hospital while I interviewed Elizabeth at their home. Two further interviews were joint with Mrs Andrew and Elizabeth at their home. I was also able to interview the family GP via telephone. Interim phone calls, where I

spoke to both Elizabeth and Mrs Andrew, revealed no significant changes so I delayed returning for follow up interviews to intervals of eight months.

Time point one:

Mrs Andrew, slim and neat with manicured nails and clasps holding her fine hair from her face, sat in a private room at the day hospital and quietly told me of her life now, but mostly about her past. She had never had paid employment but spent her time looking after her home and her family including nieces and nephews. She had been regularly involved in the world of tennis through links to clubs, players at a national level and playing herself wherever she lived. The topic of tennis peppered our interview. *'Oh yes I miss the tennis terriblyoh oh it was my life.'* She clearly missed playing and watching the sport and was struggling with this new reality *'this next week will be very hard for me because it's Wimbledon (oh) and I have to watch it and never be able to go again (oh..) and never see them'*

Her husband died two years previously and she recounted his death without reference to a personal sense of loss.. *'That's why I was so distressed about my husband [coming home to die]. (mm hm) because I couldn't bear the sight of blood and I couldn't bear the sight of anybody having a pain or anything (laughs) (mm hm) and.....I always tried to pretend it wasn't there you know.'*

However the GP described this death as having followed that of Mrs Andrew's sister, both from cancer, and as having deeply affected her patient *'[she] found the prolonged illness of her husband has been very difficult for her to cope with'*. I began to understand that Mrs Andrew may have been traumatised by watching the suffering of illness leading her to fear ill health but also that she may be repressively coping with her bereavements. She also told me of a deep seated lifelong inability to cope with body dysfunction and illness but that she was able to nevertheless remain caring and compassionate of others.

Mrs Andrew had a story for her current circumstances with a clear beginning following a fall and subsequent six week hospitalisation.

Mrs Andrew: 'I stumbled and I went flying down the stairs (oh dear) and I broke, I think it was 2 vertebrae (oh gosh) and it was here that they took me [the hospital] and I was there 6 weeks.....then I went home....but I've never really been the same you see.'

Anna: 'So how long ago was that?'

Mrs Andrew: 'Two years'

Anna: 'Two yearsOK'

Mrs Andrew: 'And eh there is just no way I could be like I was before. (OK) mentally it was a terrible shock because my life was so set up you know (uh huh), what I could do and everything and then all of a sudden I had cut out everything.'

The period provided a starting point as well as a cause *'Well, I really I'm really very strong I tell you because I played masses of tennis and ehm it was all due to an accident.'*

Elizabeth offered a similar account *'when she fractured her vertebrae,[she has deteriorated] ever since then,'* however the GP offered a much more gradual explanation of frailty increasing over a period of years *'[She] has gradually just become incredibly frail.'*

Mrs Andrew's adult son and daughter both lived with her in the flat that they had 'downsized' to. Her daughter had given up her job to become her full time carer and Mrs Andrew clearly felt the social stigma of being a 'burden' to her daughter but displaced the responsibility to others. *'The doctor said I would have to have a carer you see and eh [my daughter] said 'I am going to be the carer for you, you're not going to struggle anymore' so I said 'well' you know I felt terrible about it but she said 'don't be ridiculous'.* However she was struggling to accept her current situation *'Well I don't think I can accept it yet...'* and remained hopeful for improvement *"but I think I'll eventually get back to [previous function] because it is getting better".* Her sense of who she was now did not seem the same to her as who she was in the past before her accident *'because I keep thinking I am a different person you know.'* It was this past self, that had been a homemaker and family care giver, and physically active *'I've always been very active and eh I used to play badminton and squash and tennis'* that she described to me. In contrast her current self was struggling to

continue the homemaking roles of the past and was conflicted mixing capacity and incapacity *'I can still do quite a lot of things I like, I like, I eh liked housework anyhow, I liked it, I've always liked it and I particularly like baking (mm hm) and ehm making cakes or shortbread I like that also...I used to do my own...well up to now I tried once but I couldn't do it just couldn't'*. Over the time that I knew Mrs Andrew I began to appreciate the importance of mothering and homemaking to her sense of who she was as she readily described those as her life roles *'But that was just me happy [being a housewife and mother] (yes), that's what I liked (yes). And fortunately I never had to work.'* However the value of being at home generally for Mrs Andrew's sense of self was highlighted by Elizabeth *'She's she's a home bird really, she wasn't really one for going on holiday or things like that.'*

Although Mrs Andrew's GP worried that she was socially isolated Mrs Andrew and her daughter described a life that remained relatively connected to others via the assistance of Elizabeth who helped her visit a bridge club: *'I do take her out.....and she gets to her bridge on a Tuesday.....which she loves,'* meet friends and neighbours in a local café or for home coffee mornings. *They have a coffee morning, the group of people that she knows round about here about six of them come for a coffee morning, which she used to be able to do herself but eh.....I help out now'* and visits to the day hospital *'[going to the day hospital] has been helping her and she certainly enjoys it down there anyway'*. Time spent indoors seemed to be the consequence of a number of fears held by Mrs Andrew. Having experienced instability and falls she became ever more fearful of walking outside requiring increasing support from her daughter.¹³ Partly, though, it was the potential for public humiliation which daunted her. Further struggles with maintaining urinary continence confounded such fears. *'It curtails my life quite a bit but I have to live with it but there are a lot of things I would do that I can't because I am afraid to take the chances.'* Mrs Andrew's body was the antagonist in her story as she struggled with increasingly difficult and unsteady mobility and general weakness, yet she was

¹³ she described these fears to me as I was walking back through to the day room with her.

hopeful that she would improve. *'I think I'll eh eventually get back to [baking] because [my weakness] is getting better you know.'* However, her future beyond such hopes for physical improvement was something she feared so avoided thinking about it.

Anna: 'And do you think about your own future at all.....or is it always about your children?'

Mrs Andrew: 'No I eh,, I don't think about my own future.....I'd be too afraid (ho hoho) yes I'd be too afraid.'

Any other reference to the future was avoided by Mrs Andrew who instead focused her thoughts for the future on her children. *'Well, ah the only thing I think I worry about for the future is I think the family'*

Elizabeth expressed a great deal of frustration surrounding the care for her mother. She felt that she was not listened to: *'I know the doctors and everybody are doing em, are under pressure and everything em and when you're terribly ill, they do a marvellous job and everything ehm but sometimes you think, my goodness would you just listen to me'* that communication from health care staff was poor *'you know, you just want to know what's going on (mm hm).....you just want an actual answer'* as well as communication between health care services *'well I think the main thing is, its communication. (uh huh) Throughout the whole staff you know, nobody seems to communicate,'* and that services were simply not available to them, complaining that she had had to find everything out for herself.

Time point two:

I returned after eight months at the end of a particularly severe winter. Getting to their home was difficult, even on foot, as the surrounding pavements and roads were still thick and slippery with ice. Unsurprisingly both Elizabeth and Mrs Andrew described their curtailed freedom, however Elizabeth felt that they had entered a welcome period of stability that she hoped would continue *'but since you're on like an even keel just now, so long as things go along like that'*. Mrs Andrew's optimism had gone, and was instead replaced by expressions of loss and hopelessness *'Well, I just feel sometimes "oh, what could I do that would make it better" but there isn't*

anything I can try, you know? I wondered if she was more comfortable expressing this having met me before but there were so many explanations given that I thought not. 'As long as I can keep going but I am very conscious of the fact that it's not like that, it's always downhill instead of uphill, which I would like but I've got to realise it won't and that's the bit I don't like.' Loss of agency now dominated the conversation with many examples of what Mrs Andrew could no longer do *'I'd like to be able to clean the windows but I can't'* as struggles to maintain her domestic role to any degree were now absent and she placed these as activities of the past *'but I can't do anything like the cooking I used to do and the baking, no, I can't. So, so much of my life's changed because, well, I was married so young that I've never really worked, you see, I've always just been in the house.'*

At this interview I perceived an increase in anxiety as Mrs Andrew expressed fears of illness: *'I didn't speak to the doctor very much (mm) so I'm not saying anything because I don't want to know!'* and feared losing her memory.

Elizabeth: 'you know, her memory kind of... she can't remember things (mm-hm) really. But I think for a lot of people, when they're tired, they can't really remember things! (yeah, absolutely) But I think it just depends how you feel (yeah).'

Mrs Andrew: 'Well, yes, I suppose so but it's a worry.'

Mrs Andrew was also worried about mobilising due to recent falls

Mrs Andrew: ... 'I'm not really steady. And I guess I wouldn't be safe on my own, would I?'

Elizabeth: 'No, I don't think so. We've had one or two bangs....'

Yet she had regained a little confidence following physiotherapy at the day hospital.

Anna: 'Mm, that's good.'

Elizabeth: 'Mm-hm. and given you more confidence in walking as well.'

Mrs Andrew: 'Yes, she did.'

Anxieties, related to health, were recognised by the family GP as having been an issue for Mrs Andrew. The GP approached these creatively by taking account of Mrs Andrew's framework for understanding and was able to alleviate her patient's anxiety. *'One of her needs was she had a problem with her electrolytes when she was in hospital and became very, very anxious and neurotic about those (OK) so she*

had a NEED to have her bloods done much more regularly than I thought she required (right OK) so we managed to wean her off that.....[later] I took quite a few months to reduce her anxiety about that.'

Where Mrs Andrew remained positive was in talking about tennis. She now maintained tennis within her life by following all the international tournaments and would schedule her days and weeks accordingly. She continued going to bridge, entirely facilitated by her daughter, but was now considering giving up. Although Mrs Andrew complained of back pain towards the end of the bridge sessions and of difficulty in holding the cards due to her tremulous hand closer questioning revealed her shame at physical incapacities. What mattered was that no one noticed her tremor '*But they don't know that [my hand] shakes so I'm alright...*' and she actively further hid other symptoms of her frailty '*a lot of them say "my goodness, I'm tired!" but I never say it! (laughs) I don't want them to know*'. Nevertheless bridge evenings along with meeting friends at a local café, again fully facilitated by Elizabeth, provided social interaction for Mrs Andrew.

Elizabeth: 'Yeah, you occasionally meet up with friends at the local coffee shop.'

Mrs Andrew: 'Oh yes, I meet them on Thursdays.'

Time point three:

Arriving for the third interview, I was welcomed cheerily with a tray set for tea and biscuits on fine china. I was greeted like an old friend and both ladies enquired about my life.¹⁴ Mrs Andrew, looking paler and weaker than I remembered her, had taken to wearing fingerless gloves, was wrapped in layers of wool and complained of increasing tiredness and of struggling to keep warm. There were also physical complaints: atrial fibrillation, shortness of breath, peripheral oedema, anaemia and rectal bleeding and although cardiac investigations had been carried out, none were

¹⁴ Aided by the many telephone conversations I felt by the second and third interviews that I had really got to know Mrs Andrew and Elizabeth. I felt comfortable in their home and that I had felt less at ease at the first visit was now evident in my comfort. After the third interview they continued to chat for some time after the recorder was switched off and expressed disappointment that this was our last interview. I was sorry to leave.

planned to follow up the anaemia or bleeding. Elizabeth told me *'They were thinking of doing some investigations about her bowel problem but they said "just leave it alone"'* so I asked Mrs Andrew *'and are you quite happy [about that]?'* She replied emphatically with a vigorous *'yes'*. She clearly considered that there may be a reason for her symptoms but reiterated a sentiment of previous interviews that she simply didn't want to know. *'Well, I didn't speak to the doctor very much (mm) so I'm not saying anything because I don't want to know! The last thing I want to know about is medicine'*.

It was at this third interview that I heard Mrs Andrew's voice more clearly and she confidently contradicted her daughter on occasions which I hadn't noticed before. I think they may have been comfortable enough with me by then to do this as I had seen how close they were, and how genuinely supportive Elizabeth was, that they no longer needed to present a harmonious image. However, I saw a new confidence in Mrs Andrew, and mother and daughter chatted and laughed more openly than before. Again talk of improving remained absent, however in contrast to the hopelessness of the previous interview Mrs Andrew seemed more accepting of her current circumstances. Even in the face of her evident frustration *'No you miss [being active], you just miss....this terrible desire to go out like I did,'* she now sought ways to adapt and no longer conveyed any sense of fighting her body. Previous worries over memory loss had been allayed following assessment at the specialist clinic and she was not focused on anxieties generally. Her sense of 'self' was becoming more integrated with her body in terms that she did not talk of struggling against her body to the same degree as previously. Similarly Elizabeth's previously voiced frustration about health care services were absent at this final meeting so I asked *'are you getting enough support from the hospital or health care service or.....?'* Elizabeth answered *'yeah, they're alright'* while Mrs Andrew offered praise *'oh yes. I think they're all very good'*

Even although Mrs Andrew had chosen to stop going to bridge I was surprised to find her almost relieved with this decision which she spoke of smilingly. *'Well, I was disappointed because it was a big part of my life. Not anymore than I was with*

[giving up playing] tennis though.' In its place, Elizabeth had organised bridge evenings hosted in their home where both mother and daughter participated with Mrs Andrew passing her skills to her daughter. Similarly coffee mornings were now hosted in the flat and Elizabeth joined in. It struck me that the evident reduction in anxiety had resulted in Mrs Andrew having given up what she was struggling with. In addition, Elizabeth was scaffolding her mother in other areas by assisting with baking and homemaking activities. She would step in where aspects of tasks were beyond Mrs Andrew so allowed her mother a sense of agency and return to her previous role. Mrs Andrew had also found ways to adapt to issues that had bothered her before; rarely leaving the house by going out to her balcony to see the sun and coping with boredom by taking up reading for the first time in her life.

Mrs Andrew's self-concept was rooted in being a homemaker and in being sporty and active yet she had found a way to integrate this with the dissonance of her current physical situation in two ways. She had given herself a clear reason for her incapacity as resulting from her fall and subsequent hospitalisation. Even while she did recognise her advanced age as a contributing factor, this alone was not explanation enough *'Well I think I am so lucky because it could have happened to me years ago and I would still have been damaged (mm hm) I suppose I would have been able to do more because I would be younger (mm hm) because my age has a lot to do with it too.'* She seemed satisfied that the combination of factors gave a reason for how she now was. She also coped by following tennis avidly on TV. Tennis seemed to function as a link to her old sense of self and her old life and offered a way to still be involved in that life that had given her so much. Similarly she no longer lamented the loss of homemaking roles or social activities because Elizabeth carefully supported her to do them again. With the support of her daughter Mrs Andrew had found a new way to be herself and both mother and daughter conveyed a sense of calm that had not been there previously. Looking to the future, both wished to carry on as they were and there was no talk about dying. Given what I learned about Mrs Andrew I felt strongly that to try to discuss this would be distressing and cruel. She had seen the process of death in her home and as her daughter already

cared for her I don't think it has crossed her mind that her death would not occur in this way.

Over the period of the interviews Mrs Andrew's passive self reduced as her losses were gradually scaffolded by her daughter. She remained repressive regarding illness and would be appalled if she was given direct information about illness or dying preferring always to not know. Given the GP's understanding of Mrs Andrew over many years, she would have implicitly recognised when further investigations would be counterproductive to her patient's well-being and was keen to both limit hospital admissions: *'I think she's at a stage in her life where having to go into hospital is fraught with risk'* and to look after her patient holistically *'My emphasis would be much more on holistic care and let's look after everything about you rather than just look at your blood tests'*. The GP recognised that Mrs Andrew's frailty was at a point where her life would end fairly soon as she talked of the future in these terms *'what I think will happen she will either have a series of small, relatively minor episodes which will gradually reduce her robustness such as it is or she will have a catastrophic event which will either carry her off or will result in admission to hospital and how she progresses from there will then be contingent on whether she gets further complications.'*

6.1.1 Concluding Mrs Andrew's Story

Whilst she had struggled to cope with the losses that she had experienced in many aspects of her life Mrs Andrew had managed to reconstruct her sense of self. She had an 'it', a starting point for her decline which, combined with her view of normative aging, provided an explanation that she understood. The support of her daughter was crucial in that she understood the importance of homemaking tasks to her mother and so facilitated her continuation with these tasks in an attenuated form. Despite retreating more into the confines of her home Mrs Andrew continued to be socially connected to others who were enabled to visit again with the help of Elizabeth. Mrs Andrew herself had adapted her life to incorporate her great passion of tennis in a new way. These aspects offered a link between how she regarded her old and new

self and allowed these to be integrated. With the support of her family GP and daughter Mrs Andrew, thus appeared to have recognised the value of a supportive and palliative approach to her care as Mrs Andrew's transitioned seamlessly to a more palliative based pathway in her last years of life.

GP 'Mrs Andrew is fairly exceptional in that she has such devoted care from her daughter'

6.2 Mrs Ritchie

'We do a lot for [the carers]. Well, the kettle's all ready to boil for a cup of tea, the porridge is ready to put in the microwave.'

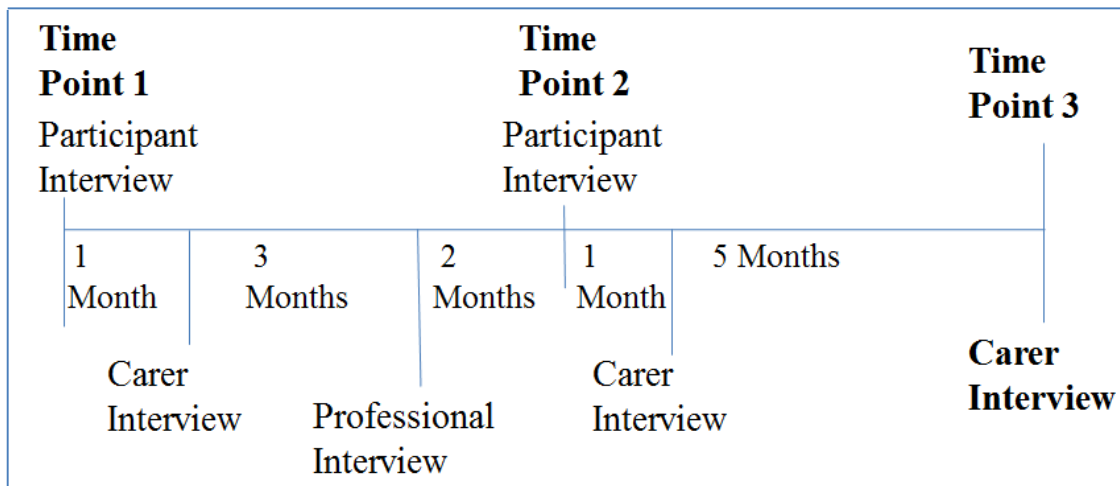


Figure 13. Time line for Mrs Ritchie

Mrs Ritchie and her sister Mrs Bird were 92 and 94 years old respectively and still very much the younger and older sister. Both were physically frail and lived together in Mrs Ritchie's home following the death of both their husbands. Mrs Bird said she would stay and listen during the interview as she was interested in the process, while Mrs Ritchie preferred her sister to stay also. However, Mrs Bird's protestation that she would endeavour to stay silent was not to be. Instead the two ladies chattered, mused and bickered and jointly told their life story. Although their stories were closely entwined, it was Mrs Ritchie's daughter (Christine) that was nominated as her informal carer therefore I will only quote Mrs Ritchie. I visited Mrs Ritchie twice and as she could not competently hear over the telephone she requested that I stay in contact with Christine. I also met Christine in her home on three occasions and it was at her request that I did not return to Mrs Ritchie for a third interview as she described her mother as having experienced significant cognitive decline. The family GP was nominated as a professional carer although only after I ran through a number of possibilities. When I did carry out the professional interview, the GP made it clear before we started that she had seen little of Mrs Ritchie and her sister over the years.

Time point one:

The ladies sat in the backroom of the stone built bungalow in chairs either side of the hearth amidst the chunky antique furniture piled with books and papers and with Christian ornaments on the mantelpiece. Once I got to know them I found it significant that Mrs Ritchie's chair faced towards the innards of the house while Mrs Bird's looked out through a picture window to the garden and the world beyond. This was a story of a life told over the two interviews and elaborated upon in detail by Christine. Starting in childhood, the inextricably linked story of the two sisters meandered through their university years and into adulthood. Both ladies spoke emotionally of their lives and experiences during the Second World War returning frequently to this period, which seemed to be the background onto which all that followed was painted. Mrs Ritchie was keen to tell me who she was and certainly had a very interesting history. Christine, who was closely involved in supporting her mother and aunt, described the childhood roots of Mrs Ritchie's lifelong insecurities and anxieties and how she had come to rely on the presence of others that were more secure, now focusing this on her older sister.¹⁵ Mrs Ritchie's GP similarly felt that anxiety was a lifelong trait for the older lady and that she gained security from her older sister's presence in the home. *'I think probably if she wasn't actually living with her sister she wouldn't be able to manage to be at home by herself anymore.'*

Mrs Ritchie offered no starting point to her current frailty however Christine attributed a knee fracture and subsequent fall which resulted in a broken wrist. Although not directly referring to this event as a starting point Mrs Ritchie recognised the impact of the wrist fracture as the subsequent weakness prevented her from putting pressure through it to a walking frame. She was frustrated by her infirmity yet held no hope that she would improve and missed such simple activities as going for a walk and described what she felt was her main difficulty *'My great*

¹⁵ The daughters of missionary parents, both sisters had been sent to Scotland to attend school and live with maiden aunts leaving their parents in Africa. Mrs Ritchie was seven years old when she undertook the sea voyage alone. The journey was traumatic as she had become ill and was put ashore at the first port to stay at the shipping office and await her parents' arrival two weeks later. Once recovered she was put aboard another ship and sent to Scotland where she was reunited with her older sister, who remained the single constant in her life.

problem is falling.' According to Christine Mrs Ritchie did not seem to consider herself as old '*they don't see themselves as old*' and certainly both ladies expressed indignation at having been told they were 'good for their age'.¹⁶

Mrs Ritchie and her sister seemed to be protected from the social isolation that their physical infirmity can engender partly by living together, but also by their local community which enabled regular outings to lunch clubs, library and to the nearby church. Having close geographical proximity to the church as well as family ties to the ministry, conferred an elevated status to the ladies. They were collected and taken to services or visited when they could not manage. *Christine: 'the church are brilliant, there's people from the church who come in on a fairly regular basis'* enabling Mrs Ritchie to maintain an aspect of her life that had always been important to her.

Anna: 'Your faith, going to your church, is it still a big part of your life now?'

Mrs Ritchie: 'Yes, definitely.'

Mrs Ritchie's strong sense of Christian duty had permeated her life. She had always worked and volunteered in helping others and when her husband died she had coped by offering her services to the local church group, as Christine described: '*she did lots for the church, going to [the church group] and would come back and say there's these poor people and they've got Parkinson's or MS and they can't talk and I sat and I just talked*'' Now that she could no longer physically assist others, she did so in what ways she could via her finances: '*I give a lot away to charity, I'm going to give £100 to the church. Because the roof's falling to bits*' or by listening to the troubled stories that some of the carers brought. Doing so seemed to allow her to live her life as she always had and I believe conferred a measure of agency to her, but also allowed a degree of comfort in being able to reciprocate care to all those that cared for her. Further social connections were enjoyed and nurtured with various

¹⁶ The sisters 'let me in' on their skincare routine which they believed had "prevented them from having any facial wrinkles" and kept them looking "decades younger than they were". They told me that other people remarked that they had "not a wrinkle on their faces". I was rather stumped for words. They truly look like nonagenarians with the facial lines to match. What a happy way to think of one's self.

helpers from the door- to-door grocery salesman to their agency carers as Christine described: *'they're interested in the carers that come in and they want to know about them and they want to have this therapeutic relationship essentially'*. All were known personally to the old ladies who chatted animatedly about these people and clearly enjoyed talking taking great interest in their lives. Additionally Mrs Bird, while engaging and friendly had a demeanour of self-confidence, ensuring that the older ladies remained very much in authority of those that entered their home.¹⁷ Other ways of coping with her reduced contact with the world and her boredom were sought as she talked of watching politics and sport on television and her pleasure at observing the squirrels and birds through the large window into the garden, some of whom the ladies had tellingly named.

In looking to the future, all that Mrs Ritchie would consider was to keep going as she was. Death was only considered in terms of its aftermath *'I look at that desk and think [large desk at the side of the room covered and stacked high with papers and books] poor Christine's going to have an awful job (hey hey hey) I was thinking that last night. Oh I can't live much longer so I'd better do something about that'* yet the subject of dying was deftly avoided each time we spoke. It was clearly viewed within the near future however had not become a concretely expected reality as Christine elaborated *'she has you know, the idea of death and dying...OOOHHHHH, GOD HELP US when that comes to it. Because that's something that they, neither of them are.....I mean my mother talks about 'this poor old buddy' (uh huh) and the poor old buddy is 66. (yes).....and they are poor old buddy's compared to my mother (uh huh) and she can recognise that but you know, god the fact, they're not ready to die'*, and a general refusal to talk about the future *'My mother does see herself as much more frail and not able to cope so much and she does say, you know "I couldn't cope without you and coming down and doing*

¹⁷ Field note: Mrs Bird seemed to be evaluating me and judging my appearance. I felt like I was at school with a teacher. I should have worn tights, as I was aware of her looking at the bare ankles above my summer shoes. She smiled warmly though. She asked all about my PhD and was like an encouraging aunt telling me to 'get it under my belt.' She really exudes calm authority and I can imagine how she retains being in charge of everything around her just by her manner.

everything you do”, which is absolutely right (Mm-hm) But take that one step further about “if I didn’t do it, where would you be?” – doesn’t want to go there, why should she? She shouldn’t.’ This was reflected in the views of the GP ‘I think [discussing end-of-life plans or wishes] would be quite a difficult thing actually to, to try to discuss with her’

Time point two:

Over time Mrs Ritchie’s physical condition deteriorated further and when we met for the second time she complained of increasing somnolence and was concerned by her forgetfulness: *‘But my memory’s getting bad (mm-hm), which is a nuisance’* which she attempted to combat by keeping her mind active *‘I say to [name of sister] “keep our brains active” so we do the crossword and we really spend AGES thinking about it. And we were very pleased we got it out yesterday’*. Her distress at bodily uncertainty was evident in increased health anxieties, described in long debated tales of calling for the doctor for various inconclusive symptoms and culminating in the conclusion *‘but there might be things wrong with you that you don’t know’* and her emerging annoyance at her lost capacity *‘It’s annoying when you think of what you used to do’*. There was an old and new self in yearning for what she once was *‘I wish I was what I used to be! (laughs)’*. This seemed linked to an increased general fear of dying and feeling of uncertainty that Christine outlined: *‘My mother wants to live forever (mm mhm) and she, the idea that they could die ... my mother has no insight that, to what’s, part, no insight and yet she’s our, she’s a hypochondriac you know, beyond belief. But the fact that she could die, I mean if you told her she had cancer now her world would come to an end, and you wouldn’t be able to re-comprehend her emotional response with the disease and that she’s 92, I mean it just wouldn’t fall into place’*. Certainly Mrs Ritchie had begun to talk much more about her day to day routines perhaps reflecting a need to root herself in the practical realities of existing in the here and now. She also alluded to her fears of what the future may hold by comforting herself in telling me about the extreme longevity in her genetic makeup and in relative comparisons with others *‘I just keep saying to myself “you should be jolly thankful you’re as well as you are.” Well, I think that’s true (mm-hm). When I look at other people in nursing homes and how ill they are and no*

children, no family... so I count my blessings'. This latter fate, the nursing home, had been broached by Christine who described her mother's rejection of the idea 'Oh God, a nursing home, I mentioned going into a nursing home. Once I said I can't have you I said if you feel you cannot cope at home (mm mhm) we would get you know you admitted for a little holiday break into a nursing home; oh, never, I don't need a nursing home'.

Mrs Ritchie continued to try to live her life in a manner that was consistent with who she was and was evident in her attempts at reciprocating care and helping others as best she could *'I give money for charity and that, it just... the different things, all these children that are starving and....'* and felt that she could aid her daily carers help her by doing what she could for herself *'Oh yes. We do a lot for [the carers]. Well, the kettle's all ready to boil for a cup of tea, the porridge is ready to put in the microwave'.*

Time point three:

Eventually Mrs Ritchie's cognitive decline was such that I could no longer visit her but instead carried out a third interview with Christine. Mrs Ritchie's main issue had become her anxiety which, intermixed with her cognitive status, expressed itself in panic attacks and extreme emotional dependency that ultimately resulted in a hospital admission as the emotional strain on Mrs Bird of supporting her sister became too much. This hospital stay was described by Christine in highly negative terms. Christine complained that she was not communicated with despite her efforts to speak to staff about her mother's situation *'I'd walked in past the nurses' station, asked where my mother was – now this is getting really... this is my age! – and not one nurse had then followed me along or said "can I catch up with you later?" or "can you catch up with me later when you go out so I can give you an update?" – Nothing. (Uh-huh.) No information chain whatsoever'.* She also complained that her words were misconstrued by staff *'I said "my mother is charming and she's lovely" I said "but if she's asked to do something that she doesn't understand why" I said "she will get a bit aggressive, you know, she will start ranting" because quite rightly, why shouldn't she have it explained to her? It's all about partnership and*

encouragement and she needs to feel she's in control and, I mean, that's basic stuff. So she obviously passed this on and when I went to them on the Thursday evening I got a distinct impression that there was an idea of "oh, [Mrs Ritchie] obviously can be a bit difficult."' Christine believed that her mother was poorly treated and infantilised as the following discussion illustrates.

Christine: 'my mother, this is the cast-iron truth, she's always been the same – even here – she instantly wakes up and has to go to the commode immediately so they accept that generally she has a wee pad and she'll just hold that while she's getting out of bed and that's quite acceptable. So she said "I rang the buzzer because I needed the commode and" she said "I needed to get up and" she said "this male nurse arrived and I said 'could I have the commode?' and he said 'what do you say?'" [pause] And my mother said "could I have the commode, you know, I need to get up?" – "what do you say first?" [pause] (laughs) So she said "please!" – "oh..." Now, I mean... so I went "god almighty!" So then I thought... well, apart from raging inside and saying to Mother "you did the right thing, you're absolutely right that you needed to ring the bell if you were told to do that, that was... you've done nothing wrong" ...'

Anna: 'Did she think she'd done something wrong...'

Christine: 'Yes.'

Anna: '...and that's why she was being treating like this...'

Christine: 'Yes.'

Anna: '...with the 'say please' and all the rest of it?'

Christine: 'But she was aware that it was rude and inappropriate and actually she said...'

Anna: 'What he said?'

Christine: 'What he said. And she said "you know, it's not..." she said "I didn't say please to begin with, 'please could I have the commode'" she said she actually... it was a rhetorical... you know, "could I have the commode?" ...'

Mrs Ritchie herself was described as being fearful of staff as a result *'So I said to my mum "I think we need to speak to the nursing staff [about the incident]" – "oh no, no, you MUSN'T, you MUSN'T speak to the nursing staff, no, no, no, no, I wouldn't*

want anything to happen”, I said “what do you think would happen, Mum?” – “No, no, no, no, because if he’s on again tonight... oh no, no, no” – now that’s fear, intimidation and bullying’. Christine brought this event to the attention of the charge nurse who apologised and promised to make investigations. No further information was provided however leaving Christine bitterly annoyed and frustrated. Mrs Ritchie was finally discharged without Christine being informed. ‘I said “so, they phoned a 96-year-old sister who lives at home who’s not even down as next-of-kin?” Actually, what happened is my aunt had phoned the ward to find out how my mum was and they’d taken the opportunity of saying that she was going home that afternoon, BUT my brother and I are down as next-of-kin and neither of us were informed’. Once home Mrs Ritchie’s package of care was increased allowing enough security for the two ladies to continue together as before.

During the whole period of hospitalisation and going back home, Christine, who was a highly experienced health care professional, raised concerns about a palliative care approach being denied to her mother. Hospital staff were described as reluctant to consider DNACPR (Do Not Attempt Cardiopulmonary Resuscitation) for Mrs Ritchie as the following description shows. *‘I asked if DNACPR ever had been discussed and the answer I got from this staff nurse was that “well, it hadn’t been discussed because everybody on this ward would be for resuscitation” and my mother certainly would be because she had come in with a fall rather than being medically unwell. And I said “yes, I agree with the fall...” I said “but she’s 93” – “oh, yes!” I said “she’s 93, she has the minimum of a clotted aneurysm” and I said “and she’s got multiple co-morbidity, osteoporosis, all the rest of it” I said “can I just ask, do you feel it would be appropriate and a successful procedure to resuscitate my mother?” – “that wouldn’t be for us to decide” and I thought “now, these are trained staff that would be calling the team if she arrested and they are telling me that they a) either think it is appropriate or b) are so gormless that they can’t make a decision themselves.” So I said “you know, I think my mother should be DNACPR” – “oh well, that would have be decided by the doctor”, I said “well, actually it wouldn’t” I said “and this would be the Lothian DNACPR protocol that’s being, you know, put out throughout all of NHS Scotland” – BLANK! Not a shadow,*

a flicker of recognition!’ Likewise the GP was described as unwilling to consider Mrs Ritchie in terms of end-of-life care. ‘Input from the GP works generally extremely well (uh huh) but I think GP’s don’t recognise.....you know.... To be offended.....and she was offended [at the suggestion that a palliative care approach should be implemented] she took professional umbrage, palliative... she could not apply that to the situation that we were in.’ ‘nothing is going to be curative. (Yes) Anything is going to be symptom management, that’s palliation, that is palliation. But she doesn’t think that.’

The GP herself talked about an uncertain future for Mrs Ritchie, however, she anticipated a reactive approach to looking after Mrs Ritchie’s needs rather than one which may implicitly recognise the end of life or palliative phase *‘when people are at the age they’re at then you know because, unfortunately something’s going to, going to happen cause that’s just the way life is (mm mhm) em but yes you never know quite when, when it’s going to be or what it might be’.*

Some months later Christine called me to tell me that due to Mrs Bird’s inability to remain in the home environment both ladies had moved to a care home in a nearby neighbourhood. Mrs Bird thrived on the intellectual stimulation of the other residents, who were described as ‘people like us’ meaning retired professionals. Residents enjoyed the personal freedom to come and go around the city with a taxi service and a general say in their daily lives that was negotiated between the residents and the staff. Mrs Bird died peacefully after a year however Mrs Ritchie, despite maintaining a relatively even keel continued a dwindling cognitive and physical decline and never really accepted her residence there. By the time of her sister’s death she was confused to the point of not being sure whether she herself was the one that had died and I worried that she would be unable to withstand the loss of emotional security that the presence of her sister brought.

6.2.1 Concluding Mrs Ritchie's story

Mrs Ritchie's story was entirely integrated into her whole life and her current circumstances. Despite her increasing frailty, up until our final interviews she managed to maintain her sense of who she was. She was physically restricted yet did not lose her connection to the outside world, to her value system and what was important to her. Whilst suffering physically from the insecurities of her failing body and psychologically from the anxieties surround fears of future illness, Mrs Ritchie found ways to still be herself, seeking emotional security from those around her, maintaining her faith and in caring for others in whatever ways she could, as she always had. The support of her daughter and the local community was, however, crucial in facilitating her capacity to do so. Where her sense of self seemed threatened was in hospital, where she was fearful and intimidated. In her own surroundings and with her support network she coped. The future was never explicitly acknowledged by Mrs Ritchie, instead she chose to live in the moment in the day to day of her life and cope with insecurities by averting her gaze.¹⁸

¹⁸ I don't know that either lady truly accepted themselves as old. They would discuss others as 'poor old souls' and told me with evident pride how they had no facial wrinkles despite appearing to me as every inch their 92 and 94 years.

6.3 Mrs Wood

'Well you've just got to accept it I mean haven't youas long as I'm.....I'm here and that's the main thing.....I mean I, I quite enjoy life and that'

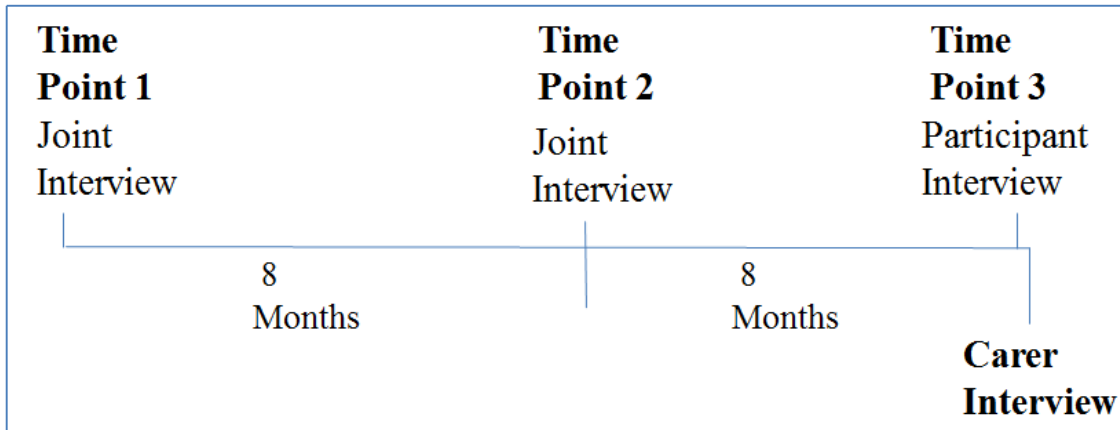


Figure 14. Time line for Mrs Wood

My interviews with Mrs Wood took place at her home jointly with her informal carer, her daughter Marjory, for the first two occasions. The final interviews, however, were carried out separately at their own homes. Mrs Wood's home was a small, tidy, three-up, two-down terraced house. She had lived there since her wedding day over fifty years ago, remaining after her husband died.

Time point one:

Mrs Wood always sat in her easy chair looking onto the street outside and regularly commenting on the comings and goings there.. The house itself was also a bustle of activity when I interviewed Mrs Wood and her daughter. Mrs Wood remained seated, her grey hair tightly curled and wearing a straight expression as Marjory showed visitors in and out of the home and bobbed up and down attending to her mother. It took me three interviews and many phone conversations with Mrs Wood to appreciate that this was simply her manner as she responded similarly to all visitors to her home. Mrs Wood's daughter Marjory lived nearby, visited many times each day and took her mother out every weekend. It was Marjory that did most of the talking during the interviews but was backed up all along by her mother's nods and brief interjections. Their story had been well discussed and picked over in the

aftermath of a period of chaos beginning with a fractured hip and subsequent replacement five years earlier. Mrs Wood had been treated with pain killers for some time before the hip fracture was diagnosed and then operated on. Subsequent multiple dislocations of her new joint led to readmissions to hospital eventually resulting in infection with MRSA and extended an inpatient period that lasted six months. Once home she suffered from an ulcer on the bottom of her foot rendering her bedridden thus confining her to the upstairs of her house for an extended period. Analgesics to control the pain resulted in disturbing hallucinations to the point that the onset of dementia was considered. As Mrs Wood and Marjory they reflected on the period they describe the events like a near-death experience.

Anna: 'you've been in the wars'

Mrs Wood: 'Oh no half eh (aye) just..... lucky to be here.'

It was a story of restitution after chaos. *'Oh we could write a book of all the things that happened.'*

This chaos period marked the beginning of Mrs Wood's story and there was a sense of life before and after this time. *Marjory: 'You know she gets a lot of visitors but as I say she just.....it's you know....it's changed her life'* yet Mrs Woods seemed to maintain her sense of self and focused on the here and now.

Her confidence in her mobility had taken a knock, however, following recent falls and although she had been attending the day hospital to try to improve her mobility she wasn't hopeful.

Marjory: 'Well then she sort of well you went to the [day hospital] after that the [day hospital] after that'

Mrs Wood: 'Twice'

Marjory: 'To get her more mobile again to try and get her and then as I say last year it all just, so she's never really been the same since 2003 I mean 2004 eh you've never really got back to'

Mrs Wood: 'Nope, no you never will eh and of course I'm worse now'

Rather than holding out hope that she would improve, the use of you as a collective personal pronoun indicated to me that she felt her assumption to be broadly or universally true. Mrs Wood spoke little of her past at any of the interviews and the

obliquely mentioned 'getting back' was never elaborated upon rather she seemed to accept her mobility difficulties. Her acceptance was highlighted in how she talked about herself within a disabled identity '*I've got to have something to hold on I (mm hm) and eh (and to lean on to) mm hm. These ambulances are no made for disabled people,*' and an older person group identity '*the young ones dinnae want to know about old people now*'. This struck me as an unusual stance yet it was when Mrs Wood told me that she had been diagnosed with osteoarthritis 40 years ago that I understood that she had had this time to integrate the physical disabilities into her life and her sense of who she was. She had a clear cause. Indeed her sense of self remained strong and autonomous and she talked in terms of what she had done to help her circumstances '*I mean I put the stair lift in myself and I mean I've put in a walk in shower*'. Mrs Wood's mental strength was given credence for her coming through this difficult 'hell like' period and was evident in her calm sense of empowerment over what she would refuse, specifically a nursing home '*You cannae make me*'. Where this changed was in relation to hospitals where she expressed events in a powerlessness manner '*I got taken into hospital*', '*they sent me in*'. Hospital stays were traumatic although she would not elaborate on specifics '*The [hospital] ah..... acht...I.....I just felt that things happened there that... (uh huh)you know.....I dunno,*'

Mrs Wood's social world had slightly eroded as she could no longer attend many of the clubs of previous years yet she was not socially isolated being buffered by a strong social support network. She had an extremely close relationship with her daughter and was visited by previous carers and neighbours in the close community. She did, however, value highly her weekly visits to a day centre, and bemoaned having lost her place following a hospital stay. Regaining a place involved months of waiting and Mrs Wood hoped to soon return to the day centre. Doing so was the main focus of her hopes for the future.

Marjory: 'I mean that's what she's said I mean really just want to get back to going to the [day centre] (mm hm) and you know that's I mean'

Mrs Wood: 'OH aye'

The only on-going complaint that Mrs Wood offered was a common one regarding the evening care service, provided to help older people get ready for bed, which arrived at 8 pm each day. This was far too early yet she had found a way to adapt and cope. *'Well they're coming in quite early but I don't go to my bed, they get me ready and I just sit and watch the television and then go to my bed when I feel like it.'* Beyond this issue, both Mrs Wood and her daughter felt that they had successfully ironed out any difficulties with care services through the years and were pleased with the care that was provided. Throughout, Mrs Wood showed her concern for her daughter and repeatedly offered to go in for respite care so that her daughter could take a holiday. Different care homes were discussed and Mrs Wood had agreed to one that she would find acceptable, although this would be a temporary measure only and both Mrs Wood and Marjory described the 'fatal' nature of a care home. Nursing homes were clearly considered during this time but were outright rejected by Mrs Wood and her daughter and regarded as something that her mother could not have coped with or even survived.

Marjory: 'Oh aye I know, I know but you're, but she more or less just told them there's no way I'm going in a home and (mm hm)'

Mrs Wood: 'You cannae make me'

Marjory: 'And that's it she just was determined and that was it'

Mrs Wood: 'Aye, no way I wouldnae be here if I'd been put in a home (mm hm)'

Mrs Wood's choice of the term 'where you are going to end up' implied that she considered a move to a nursing home may be part of her future and also that it was an end point, a final destination.

Marjory: 'But we go to a fete in the summer don't we, July, it's at [the care home] and she always says she goes in and she's like I like the smell in it you can put me in this one.'

Mrs Wood: 'And my son in law says she'll go where she's told (laughs).'

Anna: 'That's a son in law for you.'

Mrs Wood: 'Nobody knows where you're going to end up.'

Otherwise despite Mrs Wood expressing a sense of frustration at being ‘stuck’ inside her home and being unable to leave without help from others, Marjory *‘But I mean she just she can’t do any really she can’t go out oryou know I mean she’s got to always have somebody..... to take her out..... So I mean it restrictsWell I mean my mum before used to be able to just walk out the door or go and see people or go and see her friends but now her life is really here sitting in the house and people coming in you know to see her so (mm hm) I mean.’* Both she and her daughter insisted that she was contented.

Marjory: *‘You’re just quite contented’*

Mrs Wood: *‘Quite happy.....once I get going back to the the [Day Centre]’*

I struggled to understand how this could be, given how incapacitated she was, yet I learned over the course of the interviews to overcome my assumption and recognise it as a genuine feeling rather than a socially acceptable face of stoicism. She simply wished to stay in her own home and carry on as she was.¹⁹

Mrs Wood: *‘Well as long as I’m able to be eh,to be in this house, I’ll be quite happy (hmmm)’*

Over the next few months little changed for Mrs Wood so I delayed returning as long as possible and kept in touch by telephone.

Time point two:

Returning for the second interview both mother and daughter described a period of stability and of little interim change. Rather their talk echoed the stories from the first interview reiterating tales of the chaos of Mrs Wood’s difficult phase and the trials of being in hospital. Mrs Wood had begun to walk more than previously and she remained stoical and uncomplaining and confident using strong and active personal pronouns: *‘When I go to the [day centre] now and it’s like this I just take my [walking frame],’* voicing negatives only over aspects of mobility that she had

¹⁹ I could not imagine how she was contented given her restrictions and wondered if she really was. However, over time I understood that this was my bias, as she gave nothing to suggest that she was anything other than genuinely at peace.

accepted. One positive change had occurred was that Mrs Wood had regained her place at the day centre, and both mother and daughter talked animatedly about it.

Mrs Wood: 'Well last week we were watching Open All Hours, two DVDs of that. We have bingo, we have dominos, we've indoor bowls, darts, they've always got something on.'

Marjory: 'Or somebody will come in, and you do exercises.'

Time point three:

By our final interview Mrs Wood's physical situation, after a period of stability, had begun to decline as she again suffered pain in her hip. Surgery was considered but eventually ruled out due to vascular complications. Additionally she experienced increasing tiredness, shortness of breath and rectal bleeding, consequently undergoing preliminary investigations which were due to be followed up in more detail. Throughout the time I knew them, Mrs Wood and her daughter talked of being supported by their GP.

Mrs Wood: 'Oh aye.....[the GPs] come, he's coming in 2 months this time but I mean he's been coming in every month.'

Marjory: 'He's been doing it sort of,.....2 weeks, 3 weeks, you know as the time went on and then he sort of made it a month and now he's making it 2 months so I mean he has (mm hm).....he's been very good, and any time you phone up eh.'

It was then, with the support of this GP, that Mrs Wood decided to decline further investigations *Marjory: 'I mean, she got out the hospital and she just... They wanted to do it again, the test, and she just said no, there was no way and the doctor came in the next day and he says "no, no."' As she told me of this decision, she spoke in more detail of her hospital stays where she preferred to be in a single room and separated from other patients describing with a shudder and in a personally distancing manner other patients with dementia: 'there's a lot of poor souls, a lot of poor souls. I mean I don't, a lot of them don't know what they're sort of doing and it's through the night, that's when they all start. I mean the woman, the woman right opposite me, she used to shout nearly all through the night, they took her out but you could still hear her wherever she was you know'. Even though she was willing to have a blood transfusion at the day hospital she was reluctant, worrying that a*

hospital admission could ensue: *'You have to go in, aye, mm mhm. It's not that, but once they get a hold of you'* that would inevitably be extended: *'Well three times I've been there and I mean it's three months every time I go'*. Perhaps more importantly the day clashed with her designated day centre visits and would risk, once again, losing her place there.

Looking to the future, I had felt that Mrs Wood may become more open to the possibility of a move to a nursing home given her willingness to consider these for respite care; however she maintained her rejection of the idea. This was simply not an option for her future as her daughter explained. *'I had a meeting [with the doctor] and he says "oh, give it a couple of weeks and we'll see how she is" and then he just came in one Monday doing his rounds and he just said, blurted it out: "I think you should go into a home." And of course, I was crying, she was crying and she just turned round and she says to him "there's no way I'm going into a home."'* The reason for their resistance was described by Marjory when her mother was absent, as one relating to their experiences of visiting a relative in a nursing home *'Well, my nana was in one, eh, she was in [a care home] And I mean, [mum and I] just came away, the two of us broke our heart when we walked in.'* In addition they held a negative view of the consequences for older people following a move to a nursing home: *'Yeah, yeah. I mean, sometimes I've heard of people going into homes and it's amazing how they degenerate very quickly...'*

Marjory was quite frank about her mother's failing health and spoke emotionally about how she may not live for much longer, yet did not indicate that she had discussed this with Mrs Wood. Thoughts of dying did not enter the story for Mrs Wood either, and although she rejected investigations or interventions for new health problems, she chose to focus on what mattered in the here and now. To continue in her current state was the only future that concerned Mrs Wood.

Anna: 'And what do you think's really important to your mum, what do you think kind of really matters to her, keeping her going and...?'

Marjory: 'I don't know, she's got... well, she has a lot of people coming in and out and she takes an interest in what everybody's doing and she likes, you know her

[name of day centre] and she likes just getting out, eh, at the weekend, if we... you know, we take her out maybe once, twice, you know, at the weekend and she just loves it, she loves to get out and, you know, yeah, aye.'

6.3.1 Concluding Mrs Wood's story

Ultimately Mrs Wood accepted her current circumstances, attributing her situation to clear medical causes of osteoarthritis and peripheral vascular disease. She had had many years to integrate disability and physical decline into who she was and her overall story, while keeping a distinct separation from self as cause. Her sense of self never seemed in crisis having restored a feeling of normality following the chaos of recent years. She was existentially comfortable as long as she had her daughter and could attend her day centre. Her decision to forego curative treatment indicated that, with her GP's support she was moving to a supportive and palliative route, despite not openly acknowledging the end of life. Crucial to Mrs Wood's wellbeing was her connection with the outside world enabled by the strong social network and involvement in her community, facilitated by her daughter, the day centre and local friendships. Further, the close bond with her daughter remained a life constant that was closely maintained and cherished.

6.4 Miss Pegg

'See I told you all these stories about my father (uh huh) the books on the table and all that sort of, these memories keep you going, keep you alive'

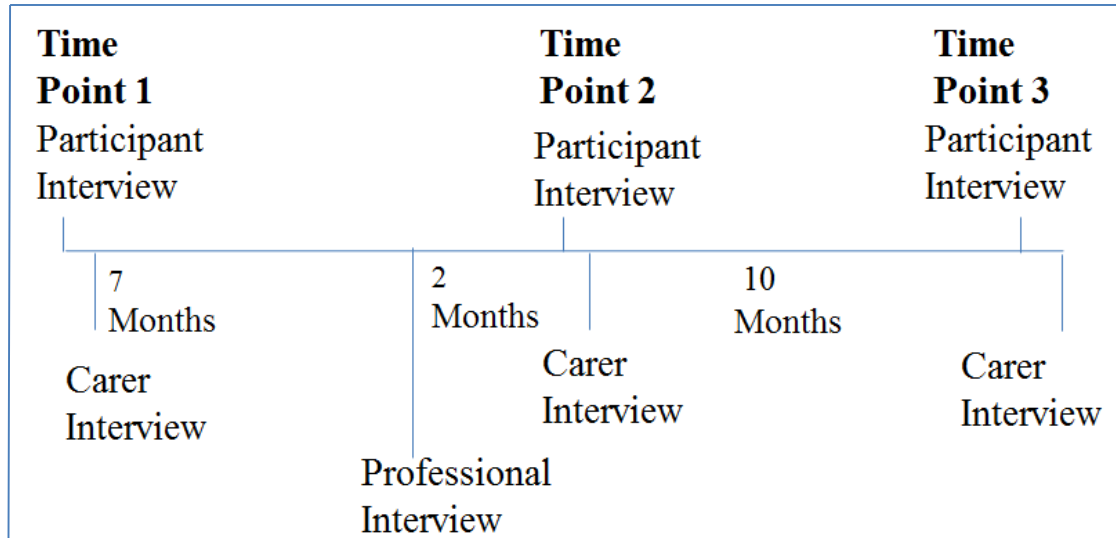


Figure 15. Time line for Miss Pegg

I met with Miss Pegg for three interviews at her home. Miss Pegg nominated her niece, Mrs Brunton, whom I also interviewed on three occasions as her informal carer and her GP, who I interviewed at the surgery, as a professional carer. Miss Pegg was an unmarried lady with no children but had a large extended family with who she was in varyingly regular contact. Miss Pegg lived in a large bungalow that had been the family home where she had spent the past 75 years of her life; remaining after all other family members had left or had died.

Time point one:

Miss Pegg was very garrulous telling me her story as she sat beside the gas fire, wearing a pale blue Fairisle sweater and trousers, her little dog curled up on an easy chair. She offered different accounts of how her difficulties had begun, initially describing a fall when her dog pulled her over leading to a broken wrist, and a subsequent hospital stay. However as she thought further, she considered new starting points. *'Oh I was alright until I had that bowel operation.'* *'I had knocked out the muscles right from the knee to the hip and that was what was causing the*

trouble.' She then thought further back to a beginning point two years previously when she required double hip replacements preceding a period of chaos with many different medical problems crossing over each other. Once these issues were explained Miss Pegg was keen to close the topic *'so there you are, that's the story.'*

Miss Pegg described her hospital stays only briefly and as uneventful, however, Mrs Brunton, elaborated on the experiences in detail. She depicted with great annoyance at the lack of coordination between primary, secondary care, social care and the family that resulted in Miss Pegg being discharged from hospital following a hip replacement with no one at home to help her. *'To me that's dreadful and 80 whatever she was [86] or 87 year old being bunged out like that with having no definite family at home or anybody to help.'*

The main thrust of Miss Pegg's first interview was the story of her life, her past and her family, where she seemed more comfortable and to which she would return repeatedly throughout²⁰. She portrayed herself as sporty, active and self-sufficient and in stark contrast to what she was now which was 'not her'. *'You see I've never really been like this you know (uh huh), and I don't know I'm....I can do that myself....'* Miss Pegg was struggling to accept her current situation feeling frustrated at not being able to do things she used to and at her lost freedom. She was striving to regain control of her body *'If I could get back'* and was willing herself to be independent again *'Once I get on my feet and into that taxi again, I'll be up [to the department store] like a shot'* yet was somewhat contradictory *'I know my legs will never get back to what they were'*. She was clearly not comfortable with having help in her day to day life and was keen to minimize her need for this.

Anna: 'OK and what other help do you get coming in day to day?'

Miss Pegg: 'Well I get the girl comes in from the carers and she helps me into my clothes but that's about all from them (uh huh) and the of course I go to the clinic'

²⁰ Field Notes: The degree of talk about the past is quite extraordinary and I am confused by it. Every topic seemed to relate back to her father and she seemed almost stuck in thinking about this period of her life and about him. Perhaps the past is more pleasant to think about for her, so is a comfort.

and (uh huh) and my niece does my shopping (uh huh) and I've got a my kitchen is pretty well easy and my nephew does all my accounts for me and eh everything and he gets me my pension (uh huh) and that and I have another niece out at West Linton and she's pretty good at coming too (mm hm) and everybody's round about me you know (mm hm)'

Anna: 'And what about, you know day to day things like cooking, you manage that OK?'

Miss Pegg: 'Ocht no bother'

Anna: 'And cleaning and um?'

Miss Pegg: 'Well I have eh , I have eh, I didn't tell you that, I have 2 people come in on Monday and 2 people come in on Thursday eh privately and ehm (uh huh) they come in and they do all my hoovering and dusting for me (uh huh) and [the gardener] of course comes in on a Monday for four hours and does the garden (OK) so I'm alright.'

Anna: 'You're grand. And you manage to have a bath or a shower and'

Miss Pegg: 'Well, yes eh because I had a shower this morning because [carer] comes in and eh on a Tuesday I have a shower so....'

Anna: 'So that's your'

Miss Pegg: 'Eh mind you I'm sure I could get in to the shower myself.'

Miss Pegg talked openly about her frustrations, *'this broken wrist, I mean I've never, I mean the rest I, I, I have face up to it and I can do it, oh go out and ocht, I'll do that alright, but this has scuppered me! (uh huh) and I'm frustrated'* and admitted to feeling down, although this was clearly difficult for her to be open about as she used light language and humour to minimise her feelings.

Anna: 'OK and do you feel do you feel within yourself as happy or.....'

Miss Pegg: 'Well.....[sigh] sometimes I think ocht damn what am I sitting here looking at a TV for you know (uh huh) but that keeps me ocht, get off ma shoulder wee dark man and eh that you know'

However, Mrs Brunton felt that this was a greater problem, describing her aunt admitting to feeling depressed *'you know she's said to me before ocht I'm depressed*

you know she says I'm quite depressed' Following this line of conversation Miss Pegg appeared to cheer herself by returning to the story of her own life and that of her family, involving greatly detailed descriptions of the many characters, spanning all the way back to her childhood and encompassing many other family members, yet remaining almost entirely in the past. The past was the focus and this is where she seemed most comfortable. *'That's the story of my life dear,' 'so that's the story of the family too'.* Her father remained a dominant influence on her and was ever present and she told me in detail of his character and exploits, carefully explaining to me as she did so, who she was as embedded in this family history. Her father had built many houses in the surrounding area, including the one that she lived in. Thus her geographical location was of special significance to who she was, which, even at this grand age remained static *'I'm the builder's daughter'.*

Socially Miss Pegg described connections with neighbours and with old friends from her youth about whom she told detailed stories. Social interactions were valued by her and she was certainly friendly and garrulous and enjoyed being out in the world with her dog. However Mrs Brunton described her aunt's recent circumstances as being confined, indeed imprisoned, within her home *'Right now she's been incarcerated if you like for the last five weeks.'* Given Miss Pegg's connection to her family history, I was surprised that living relatives were minimally mentioned at the first interview, although her Mrs Brunton explained that relations between her aunt and others in the family were strained.

Miss Pegg talked of many things that she felt she had lost and seemed in one sentence to have accepted these losses: *'I can't do everything I used to do'* while in another fully expected to regain them. *'Well I hope I get back to normal'* albeit within an attenuated form, *'I mean I and mind you I've never been back to what I was but I hope I can walk my dog'.* She remained optimistic for the future in terms of improving her physical capacity *'Well the thing is, I'm beginning to feel this ache in this hip which shows I think the eh the beginning tosort of come back to normal you know.'* The word normal was crucial here. Miss Pegg simply wanted to be normal. Like many in the study she was keen to point out her mental status as

alert and vital almost in contrast to her physical state. *'Well that's the it's the frustration of this (uh huh) because mentally as you can, I'm quite alert as you know'* The future was about striving for restitution, about recovering her physical ability and 'getting back' to previous function or at least perhaps to a new normal. Although she offered an implicit statement that suggested she had come to terms with her life being near its end, *'I've had a good life,'* however talk of actual death was absent.²¹ Miss Pegg was determined to try and overcome her difficulties and look after herself and there was a morality to her story of coping and 'getting on with things' that was clearly being sorely tested.

Time point two:

At the second interview I found that Miss Pegg had improved and was much more upbeat. The difficulties of the previous interview were dismissed as now behind her. *'So honest to goodness it was just a chapter, over two years it's just been a chapter of one thing after another but I'm alright,'* and she distanced herself from this period in terms of her daily life *'I do everything myself now'* but also in her sense of self *'and that wasn't me [having messy hair]'*. Her previous occasional admissions of low mood were now also rejected as not like her, *'you know I've never been a depressed person, I never have been in all my life I'm really buoyant you know.'* She offered retrospective explanations for why she was feeling better, *'[I'm not down now] because I can get out and talk to people.'* She was optimistic that her improvements would continue *'I am back on track, it's just a case of getting the legs back.'* She inhabited the 'now' in her conversation with me and in striking contrast to our previous meeting, she talked little of the past.

On a practical level Miss Pegg was physically managing a little better than previously and had dismissed all help other than her cleaners, citing both the irregularity of their arrival but also a belief that their help was not fully needed. *'And*

²¹ I assumed at this point that Miss Pegg was accepting of her death, yet a later interview revealed that this was far from the case and she may have been offering to me a more socially acceptable rationalisation that she perhaps felt.

sometimes they didn't come early, sometimes they came late so it got to the stage where I was into my clothes before they came if they were late you know. So I just said somebody needs them more than me.' However she was also now managing regular outings to buy groceries via the dial-a-bus service with practical help at a nearby supermarket. Mrs Brunton explained that waiting for the carers meant that her aunt risked missing her weekly trip on the dial-a-bus. The service was cherished by Miss Pegg, who revelled in the social contact it provided *'Oh we're a great crowd on that bus we have all sorts of fun you know and the men, I think the men quite like our bus because it is a cheery bus you know and so you know it's very nice.'* This statement also conveys a sense of group identity and belonging with the group that used the bus. It appeared to be the 'normality' of this everyday activity and with people that she felt that she could relate to that Miss Pegg relished as she dismissed the suggestion of attending a day centre..

Miss Pegg: 'No I don't go to the day centre no. The thing is I've got the dog and I run my own house and I've got I get my own messages, I go by the dial-a-bus you know, and I go out and do my own messages, I've got something on every day.'

Anna: 'Mm.'

Miss Pegg: 'And really the day centre's not for me you know.'

She felt that she had plenty of company and talked animatedly about her family and all their gatherings that she attended. This time her focus was on relatives that were alive rather than deceased. Mrs Brunton explained that the family disputes that her aunt had been part of had now resolved so that she was able to connect better with the family again. It was here that I began to understand the complexities of Miss Pegg's talk about her family. At first I believed that it was simply a method of distraction from current life difficulties but later saw it as more than this. She needed me to know who she was, which was so deeply ingrained in the fabric of her family and particularly the dominant personality and status of her father at its head. She also may have been struggling with feeling adrift from her current relatives, so she had focused on talking about those in the past, whereas now she could direct her attention to those that were currently around her. She was however, rooted in her community, feeling herself to be a known local character. She kept visible by still going out to walk her little dog which also brought neighbours in to visit her. *'My*

neighbours look in and say how are you today Miss Pegg, they bring their dogs in with them and everything'.

Although Miss Pegg had regained a degree of physical function, it was not to the levels that she had hoped: *'I wish I could get my legs back to where they were when I was riding and skating and everything like that but that'll never be.'* Yet she seemed to have adjusted to these losses, reassuring herself that she remained cognitively intact. As for the future, Miss Pegg was positive though in a more dismissive manner. *'No I don't worry about the future'*. She elaborated on a future death but only regarding the distribution of her personal belongings *'I'm eighty nine now so someday I'll go, I've got all my will down and everything you know and everybody knows exactly what they're getting'*.

Following this new found period of stability, I attempted to stay in contact with Miss Pegg via the telephone as before, however she had begun, again, to require emergency hospital admissions. I managed to arrange a third interview with her although on arriving at her house found it shut up with no one home. Phoning her niece I found that she was in hospital having been admitted the previous evening. Thus the final interviews took rather more months to carry out than planned.

Time point three:

Miss Pegg had begun to physically deteriorate. She was having frequent falls and increasing breathlessness due to heart failure and had faced periods of hospitalisation. Having been discharged from hospital with a package of care, Miss Pegg once again dismissed the service: *'In fact, when I first came out of the hospital there was a girl came in and helped me to dress in the morning but do you know, I couldn't be bothered with it because I had to wait till she came and sometimes it could be nearly eleven, half past eleven and I'm still sitting in pyjamas and... you know. So I said no, I would manage myself. And I do manage myself without any bother.'* Again Miss Pegg had dismissed the help of carers explicitly now blaming the interference with her weekly dial-a-bus outing.

She was now walking very little and her niece explained, trying to encourage Miss Pegg to get outside. *Mrs Brunton: “look out in your garden and you can see all the snowdrops and stuff like that” and she goes “yes, I should, I should” but she’s not going for a walk round the garden. And it’s a nice flat garden, I mean, you know yourself that she doesn’t have a whole load of steps or anything, it’s all nice and flat, she can go out the front door and in the back for a nice wee walk round, you know.’* Her activity levels had also been impacted on by the loss of her dog *‘and of course, since the wee dog has gone I’m not walking so much’*. Yet Miss Pegg explained how the effects had extended to her social interactions *‘I would go out and maybe some of the other folks would be passing with their dogs and I’d have a chat with them and things like that, you know’* and connection to the outside world *‘everybody out round about with dogs knows me’*. The dog had given her company but also the incentive to open the door and be out of the house thus a reason to interact with others outside and she clearly missed it.

Miss Pegg: ‘It is when I close the door, just when it’s dark now, that’s it closed for the night, you know.’

Anna: ‘Mm. That doesn’t feel so nice.’

Miss Pegg: ‘And before that it was always open because I’d open the door for the dog or shove her out in the garden if she wanted to do anything, you know. And I would go out and maybe some of the other folks would be passing with their dogs and I’d have a chat with them and things like that, you know.’

Accordingly Miss Pegg was now socially reliant on the weekly dial-a-bus trip and on her extended family. The dial-a-bus outings allowed her to still be her sociable outgoing self as Mrs Brunton illustrated in the following event *‘whatever she said she was that day and [the bus driver] says “is it your birthday?” and so he took her on the [dial-a-bus] and he said to all the different people – of course, she knows them all by name now, they go all round [the supermarket] and all over the place picking up these people – and she said [the driver] said “this is Miss Pegg’s birthday today” and so the whole bus sang “happy birthday to you” you see. And then when she came out the driver and all the folk had a – what do you call it? – a collection and bought a big bunch of flowers out of [the supermarket] for her, you know’*. Mrs

Brunton also described the impact on her aunt when the service was temporarily unavailable *'during the snow when they said [the dial-a-bus service] weren't coming, you know, because they couldn't get the buses moving from where they come from up the other end of town, oh she was really depressed, you know.'*

It became clear that the type of social interaction on the dial-- bus was unthreatening to Miss Pegg in a way that interactions with others in hospitals or care homes could not be: *'Oh, well... I'm a sort of social buddy, you know, I've always been one of a big family and...(Mm-hm...)...you know, when I go with the girls in the bus they all said "oh hello Miss Pegg come on!" you know, the things like that and like we have a good laugh but in hospital there's nothing like that, you just are... everybody's ill'.* Similar sentiments were expressed to explain Miss Pegg's resistance to moving to a care home as explained by Mrs Brunton. *'People with dementia [in hospital] and she didn't like seeing that either, to her that was horrendous and I think probably it's something to do with that, you know.'* It was this very problem of social interactions that Miss Pegg complained of in the hospital and in other settings with older people. Specifically she was reluctant to connect with 'others' there that she did not seem to identify with. *Mrs Brunton: 'once before she did, you know, she said "oh, old people there" you know, and she doesn't consider herself as an old person, you know!'*

The only situation that seemed to counter such a view was the day hospital, perhaps because there was a distinct purpose in terms of various therapies for going there. *Mrs Brunton: 'she was quite pleased with [the day hospital], she didn't turn round and say "oh, there's an awful lot of old folk there, you just don't want to go."'*

She now told a clear story with a settled starting point for her difficulties which also allowed a cause *'what really started all this in-and-out of hospital was that I had fallen and knocked out one of my hips.'* She continued to define a before and after evaluation of the self: *'it's about two and a half to three years since this started and I never was ill before that'.* This allowed her to distance herself from her physical difficulties with the self of before as the real self, whereas the current self was 'not me.' *'Well, I say "never been ill"'. Miss Pegg remained accepting of physical*

decline and no longer clearly hoped for improvement *'it's just a general decline, you know, just a... I just feel I'm not doing as well as I used to, you know.'* Resigned that a full return to previous function wasn't going to happen, she envisaged a gradual, inevitable decline *'Well, I might get a bit better but, you know, every time I go in and something happens you never quite get back to where you were.'* Stories of the past emerged again as a distraction but I think also to allow her to re-engage with her old self before she became physically frail.

Given Miss Pegg's recently emerging acceptance that she would not improve, I asked about her thoughts on possible future deterioration yet she didn't answer directly instead shifting again to the comfort of her father as the authority figure. *'Well, I would... I would get... you know, I'm a great innovator for certain things, you know, I can get... I mean, sometimes I just hook my things with this walking stick in there and things like that. Father was the same, my father was never stuck.'*

Following this she looked more directly to the future and considered her death.

Miss Pegg: *'No I don't worry about the future.'*

Anna: *'Uh, uh.'*

Miss Pegg: *'I'm eighty nine now so someday I'll go'*

This made me think that she was at peace with her life ending, yet Miss Pegg was not in any way ready to die, or accepting of her own death as the following discussion around a potential malignancy illustrated.

Anna: *'And are you happy to go in and have [a newly discovered breast lump] investigated then?'*

Miss Pegg: *'Oh aye!'*

Anna: *'OK.'*

Miss Pegg: *'I'm not worried whether they find it's definitely...'*

Anna: *'OK'*

Miss Pegg: *'After all, nearly 90, goodness god, you've got to expect things to happen to you.'*

Anna: *'And if they wanted to treat you, what do you think you would do?'*

Miss Pegg: *'Oh, I would accept the treatment, oh I certainly would. (laughs) I wouldn't let the grass grow under my feet there! (laughs)'*

Anna: (Laughs)

Miss Pegg: 'Because I mean although I say "I'm nearly 90, you've got to expect these sort of things" I'm quite willing to live a long time if I can!'

Despite her struggles Miss Pegg continued to enjoy life, particularly when socialising with others.

Anna: 'Do you still enjoy things as much as you ever did and...?'

Miss Pegg: 'Oh, I do! (laughs) 'Oh yes, when I do have things, parties and things like that, I still enjoy myself.'

Miss Pegg summed up her joie- de-vivre memorably.

Anna: 'And what keeps you going, what's your thing in life, what keeps you... what gives you meaning and...?'

Miss Pegg: 'It's just the fact that you're living. (laughs) You're alive, at least you're alive! (laughs)'

It seemed that there were fates of living in a nursing home or becoming demented that Miss Pegg felt that she could not bear and would make the life she loved not worth living. *'Whereas if you had no mind and a good body what would you do, you'd just go shuffling around wondering where you were, mind you you'd be quite happy doing that, but I wouldn't be happy doing that I would rather be away than have that.'*

Miss Pegg looked at the future but only thought in terms of what she hoped to avoid. The idea of moving to a nursing home was dismissed for her own circumstances because of the exorbitant cost when she wished to bequeath the value of her estate; itself tied up with the life's work and ethics of her family in particular her father, to family members. However further exploration revealed that to go to a nursing home would simply not be consistent with her self-image.

Miss Pegg: 'And [being in a nursing home] wouldn't be sociable enough for me.'

Anna: 'Uh-huh. And do you think it would make you feel...?'

Miss Pegg: 'Aye, old and done and you might as well kick off! (laughs)'

Such feelings extended to other settings however, where she wished to distance herself from others with dementia. *'I couldn't abide being in the ward where all the people are old and done and not able to speak and things like that.'*

Mrs Brunton told me of her aunt's views about a nursing home. *'She... oh, thought it was terrible, the whole thing, you know, that [name of sister] was in there. Of course, [name of sister] was a lot younger but she used to think "oh no, I couldn't... never, never, never, never put me in something like that" she would say.'* She also explained Miss Pegg's deep connection to the house that she lived in.

Anna: 'Does she feel that she wants to leave the financial legacy behind or to...?'

Mrs Brunton: 'No, it's the house, the actual bricks and mortar.'

Miss Pegg's sense of who she was, was so deeply enmeshed with her place in her past and her family, itself embedded in the family home that had been built, like many in the area, by her father's company.²² This home connected her, rooted her to her history ... *'a great pride in the family tree and she's got me as daft as her about that, you know. And I can go back with her lot and with the other side away back 200 years and name them all sort of basically and that sort of thing and the ages and the dates and the stuff, and so has she and she'll say "of course, great-grandma so-and-so" and she likes nothing better, when I go there she'll get back onto these subjects, that is really... LOVES to do that, talks about that, the background, the family, the set-up, you know. And that's why the house is important.'*

²² After our first interview I was perplexed at the degree of talk about the past and about her father. I thought that she was choosing to focus on the as a way of avoiding distracting herself from her current life. However, as I got to know her I realised that, although distraction may be part of it, that those discussions were primarily aimed at describing to me who she was. Her sense of self was so deeply ingrained in the fabric of her family.

6.4.1 Concluding Miss Pegg's story

I left Miss Pegg feeling that she was managing to integrate her story by connecting the self now to the self of the past by still 'doing for herself' when she could, by maintaining social interactions and connections with the world via the weekly shopping outings, while remaining in her own home and rooted her to her history. Furthermore, the loss of her physical capacity was integrated by allowing a bad fall and subsequent hospitalisations to provide a cause for the decline she now faced thus removing the responsibility from the self. Ironically this cause offered a link, a bridge, from the self of the past to the self of the present. I did, however worry for Miss Pegg. Losing her capacity to continue on her dial-a-bus outings, or more importantly, her capacity to remain in her own home, would be existentially catastrophic to her and could obliterate her current passion to hold on to life. By avoiding settings designed for older people Miss Pegg could avert her fate of being what she considered as worthless. Not only because of what she would lose but because of what she would become: '*old and done*'. Whatever the future holds for Miss Pegg, I suspected that she would resist any attempt to move from her home. It was a symbolically important link to all that she held dear and valued in life. If her circumstances became such that she could no longer reside there I am not sure that she would manage to adapt.

6.5 Mrs Baxter

'If I go on deteriorating as I'm doing it'll be quite long enough'

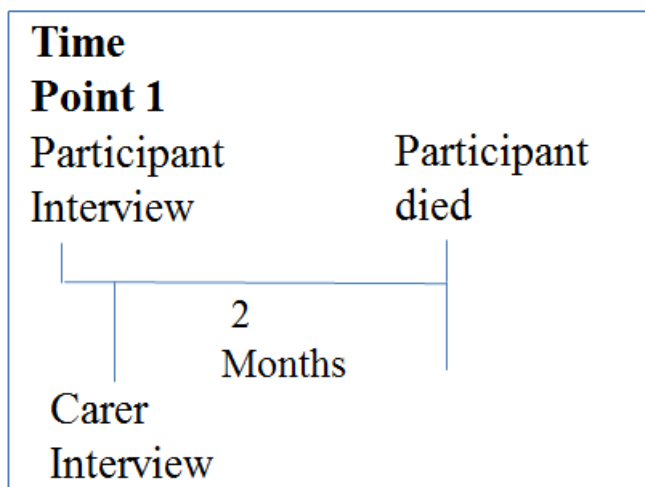


Figure 16. Time line for Mrs Baxter

Mrs Baxter was the only participant with whom I carried out only one interview as she died within eight weeks of visiting her. I had initially hoped to be able to speak with her husband also. However on arriving at their home Mrs Baxter said that he was busy with paperwork and that I would be better speaking to her son Alan who, despite living in the USA, she had a close relationship with. I managed to carry out a telephone interview with the son, however the quality of the recording on the transatlantic call rendered it un-transcribable so that I had to focus on the notes that I took during our conversation.

Mrs Baxter lived with her husband, who had an advanced chronic condition, in a top floor flat on a grand Georgian building situated in a quiet and peaceful city centre street surrounding a private park. The flat was accessed through a main door followed by three flights of stairs to a second door which then was followed by another, much narrower flight of stairs to the front entrance to the property. A stair lift had been installed to the third floor and then another to the front of their home.

Time point one:

On arrival I was met by Mrs Baxter and ushered through to the living room while her husband, who struggling a great deal with mobilising, absented himself using his walking frame to another part of the flat. The main room had high ceilings and was lined with bookcases housing large hard backed tomes. Mrs Baxter herself was slightly built and bent in posture and walked very slowly with her walking frame, while her keen eyes tracked mine as I took in the surroundings. She was softly spoken with a private manner and seemed terribly tired. She had qualified in a profession in her youth but after marrying opted to become a full time wife and mother to her two sons. They had lived, as a family, in various parts of the world but had settled back in Scotland for her sons' school years. Both sons now lived in the USA and she was keen to tell me after the interview tape was switched off that she was happy that they had chosen to live their lives away from her and her husband as that was what she and her husband had done and was how it should be. She was also keen to impress on me that her life of caring, both in the past and in the present, is exactly what she wanted and that she would not change even although it was now exhausting for her. She felt that this role represented who she was and who she is. In this respect she had managed to maintain her sense of self by continuing in her caring and homemaking roles. The interview was quite slow moving and punctuated as Mrs Baxter became drowsy then roused herself, however when she began to doze off a second time I decided to terminate the interview. She woke herself to talk to me a little more as I was preparing to leave and then rose and walked me to the door.

Mrs Baxter told me the story of her current life and how she came to be as she was and the circumstances surrounding the care of her husband. She did not offer great detail to me about her life describing the past only insofar as to illustrate to me the story of who she was, who she is and to a lesser degree, as a contrast to how her life was now, in wistful musing of an idealised third age. *'We had, after my husband retired, we had a few very good years when we lived a most enviable life because we were able to retreat in here during the winter but we went out to the States for fairly long visits and eh we've one son in, in eh [USA STATE] and the other has been moved about rather more but present he is in [different USA STATE]. And so we*

were able to visit them and that took the worst of the winter away and then we probably during these regrettably few years, probably spent about six months each year in the countryside where my husband played a lot of golf and took a, a very active part in running his local golf club.'

Mrs Baxter pointed to the critical time point where her frailty began following surgery for bowel cancer, *'I think it was when I had reached the age of 80 and then I had this bowel cancer and sickness of, just very gradually deteriorated since then.'* However she attributed her current situation to a clear medical cause that was a malabsorption difficulty that had led to osteoporosis, subsequent reduced mobility and pain, weakness and weight loss. *'It was all agreed by my advisers that I had a malabsorption problem and my difficulties arose from that.'* Her physical condition was thus a linked chain of events that made sense to her. Physically Mrs Baxter was experiencing considerable pain that was controlled somewhat by medication yet resulted in marked sleepiness. *'At the moment because I'm, and for some time recently, because I have a great deal of pain I'm on painkillers a lot and they make me drowsy and not only do I sleep at night but I sleep at least twice for period during the day (mm hm) and I don't mean 20 minutes or half an hour, I could lie down after lunch and be deeply unconscious for a couple of hours. So it eats into the time tremendously'.*

In terms of day to day life Mrs Baxter had been receiving assistance for some time, however the manner in which she spoke about those that helped her conveyed a sense of normalising her difficulties and of maintaining control over her world. She talked about *'my case'* when referring to her medical problems and to doctors as *'my advisors'* and those that had come to help care for her and her husband as a *'man carer and helper'* that provided services rather than care *'[we have had] the services of a man carer and helper who does quite a lot of housework'*. Other care help that was arranged by health and social care services was referred to as *'visitors'* and dismissed after a short time. *'[My husband] declined more, he could have had more assistance but he's very independent and he had all that he wanted and for a period when I came out of hospital we had another visitor who came in later in the day but*

after a while he didn't think that was necessary so we haven't had that for some time'. From Alan's perspective, carers that had been coming, primarily for his father, had been changing and he described 'large numbers of players involved'. He felt that to have someone sorting out everything and having regular people would mean that his parents could get a feel for the person and that they would then get a better understanding of his parents needs from a more holistic rather than task orientated approach.

Mrs Baxter's inability to physically do things had affected her self-worth: *'simply an inability to do things. I feel like I've become a perfect nuisance. Not that people make me feel like that but I just feel useless.'* This caused feelings of boredom and frustration. *'I feel a bit bored with myself really em so many of my previous interests are now not available to me and yet at the same time I just don't have time to indulge them anyway (mm mmhm) because I do so little, get so little done, so there's a thread of, of frustration runs through my days.'* She also missed the outdoor activities that she could no longer manage. *'We were reasonably active, miss not getting out and about, miss... being shut up indoors. I don't mean I miss being, I mean I'm restless, the, the outdoor activities...that keep me shut up indoors.'* However the degree of indoor confinement was not helped by their residence which Mrs Baxter's son explained about. Reaching the ground floor required using a series of stair lifts which took 25 minutes for both husband and wife to reach the main door meaning that any trip out for the couple required a considerable time frame. Equally, despite Alan's frustration at his parents' refusal to move to a home that would have suited their needs, he understood their deep attachment to the city flat that was the family home.

The importance of this home was reflected in Mrs Baxter's whole sense of self. Her dominant life roles had been of a wife and mother and she regarded herself almost entirely in relation to the others in her family. She talked of her decision to give up her profession and focus in her role of taking care of her children when younger *'on the whole I became, not unhappily, simply a wife and mother with the usual sort of interests and activities that wives and mothers have.'* This wife and mother role continued to the present as she talked of herself and her husband as 'we' and 'us'

rarely using the singular. Again, her phrasing of the decision to decline further assistance utilised terms that implied household, rather than personal, help; thus distancing the threat to the sense of self. *'I think we have as much domestic assistance at present as we require'*. This insistence on caring for her husband while refusing further outside assistance vexed her son, yet equally he stressed how important this was and could see that removing this role would be detrimental to her. It would be like taking away who she felt she was. He did, however, lay some of the responsibility of this on to his father, who he described as being very stubborn and not willing to take increased help. It seemed that he felt his mother was left doing her duty as she has always done, and that her quality of life suffered accordingly.

Mrs Baxter did not offer a sense of herself as part of any wider collective with other older or frail people but her collective identity was restricted to the family, as it always had therefore remained within a normalised life framework. Despite both of her sons living in the USA, both Mrs Baxter and her son talked of maintaining a close relationship. *Mrs Baxter 'Oh yes, [my sons and I] spend all Sundays talking on the telephone. em, they're very, they're very concerned but they're very close with us and one of them is married with three children and eh so. From that point of view things are and I mean they live overseas as they've chosen their life, as we did ourselves em they're not able to visit us very often but we, we are in close touch.'* Alan worried about his parents being socially isolated and this was something that his mother openly admitted *'We are very isolated because we never had a large circle in Edinburgh, we came to Edinburgh and treated it as a pied a terre when our sons were at school in Edinburgh and we ourselves were out of the country.'* However this was not something that she viewed as problematic, complaining rather about seclusion from the outdoor world.

Mrs Baxter: '[we] have outlived a good many of our contemporary friends.'

Anna: 'okay. And is it something that you miss, do you feel at all isolated in yourself?'

Mrs Baxter: 'Not particularly, we, we have never been gregarious and no, my husband on, at the moment he's chafing a bit about being so much indoors.'

Mrs Baxter: '[I] miss not getting out and about, miss, miss being shut up in doors.'

Looking to the future I found that Mrs Baxter was initially dismissive of giving any consideration.

Anna: 'And eh do you have any thoughts about what you'd like to see happening in the future or how things will go for you'

Mrs Baxter: 'For me?'

Anna: 'Yes'

Mrs Baxter: 'not particularly'

However further enquires revealed that Mrs Baxter was very much aware that she was dying and that this would be quite soon. She seemed completely at peace with this idea expressing no fear or regret and so lent an air of resolution to her story in that she had lived her life as she would have wanted it and would soon die.

Anna: 'OK, do you ever think to the future?'

Mrs Baxter: 'Just gradually wind down I guess'

Anna: 'OK and how you would like to live the next few years, any thoughts'

Mrs Baxter: 'Well, I don't expect to live very many'

Anna: 'well the next wee while you know that you are living which you know may well be long enough [a while], are you happy with the way...'

Mrs Baxter: 'If I, if I go on deteriorating as I'm doing it'll be quite long enough'

Similarly her son felt that she was resigned to her situation and had been told by their doctor that she should 'get her affairs in order'. He therefore had the impression that his mother knew that she would not live for much longer. Instead she focused on living her life in the moment and from day to day. *'I really just take life one day at a time'* and found existential comfort in her caring roles and relationship with her sons. *'Well I've always been a personal, a person with a, a deep attachment to the family and really since my husband's illness my life simply resolves around him (mm mm) and I think that's what keeps me going mm.'*

Mrs Baxter seemed to be trying to help me, but at the same time I did not feel that I scratched below the surface so I was hopeful that I'd be able to pick up on some of the cues during this interview and follow them up with her in more detail when we next met. I had also felt that Mrs Baxter was someone whom I would get to know over the course of the follow-up interviews as she had struck me as very private.

However, on talking to the Alan I had mentioned hoping to get to know his mother better and he had joked that he wished me luck as his own wife had only very recently felt that she had got to know his mother.

Having interviewed Mrs Baxter I was also left with the impression that she was so very exhausted and that this was a general state rather than being peculiar to the times that I had met her (at the day hospital as well as her home). I did not think that she would survive for the year of the study and I resolved to try to return to see her as early as possible. I spoke with her after eight weeks and she told me that there was no change in her circumstances or medical condition. I booked the date to go back to her two weeks hence, but unfortunately I was informed by her son that she had died, peacefully at home, a few days before we were due to meet. I had already spoken to Alan in the interim period and was aware that he had not since been able to visit his mother, so decided that I would not gain any more detail from a bereavement interview.

6.5.1 Concluding Mrs Baxter's story

Mrs Baxter experienced many of the same issues as other participants in the study. She suffered from pain, reduced mobility and tiredness. She also missed going outside and being 'shut up' indoors as well as a sense of being a nuisance. She was rather bored and frustrated and weary of life, nevertheless she was insistent that her way of life was focused on how it had always been. Looking after other people was who she was as well as what she did, and she held on to this. Thus she remained unwilling to consider extra assistance in her husband's care. Having the financial means to 'buy in' outside help enabled her to have assistance in exactly the way she wanted it, which was as much to do with household chores as physical needs, but also facilitated a sense of continuing control in her life. Although, Mrs Baxter and her husband were socially very isolated, this was not a source of distress as she explained that neither had been overly sociable in their lives. Instead they focused on family ties which, despite her grown sons both living on another continent, were regularly maintained and brought much comfort.

I had felt that her death would be soon and when I heard that Mrs Baxter had died I wondered if perhaps her life may have been easier if the couple had moved to a more convenient dwelling as her sons had yearned for them to do. Nevertheless despite the likelihood that the last few years may have been a struggle, I did not feel that she had suffered unnecessarily. I have to acknowledge, though, that Mrs Baxter was the only participant that I interviewed only once. I did not, therefore gain much understanding of change over time. However my conversation with her son allowed me a glimpse of her history and way of living. Neither was I able to return to Mrs Baxter and build on any relationship, although again, her son was emphatic that his mother was extremely private and that I would have been unlikely to ever feel that I knew her. Mrs Baxter acknowledged that her life would soon end, was at peace with this fact and weary of her daily struggles and failing health yet she died maintaining the way she had lived and without losing a sense of who she was. Her story had a clear beginning and cause, with an anticipated and looked for ending. As Mrs Baxter's frailty accumulated, she knew that her ailments would not resolve, so focused on managing her symptoms, her life coming to a close as she had expected.

'When you've lost your health is, is the one and only thing I think that when you've lost your health you've really lost most of what makes life worth living.'

6.6 Bringing the stories together

All these older people experienced physical decline over the course of the study yet managed to maintain their sense of self. While they experienced losses in the other dimensions of their lives, they were able to adapt to and make sense of their circumstances. These were stories of restitution even to death.

Miss Pegg and Mrs Andrew were initially optimistic that their situations would improve and they could regain a degree of function. Over time this was not to be, yet both managed to adjust to a 'new normal': a restitution of normality. In contrast neither Mrs Ritchie, Mrs Wood nor Mrs Baxter held much hope for a return to previous function but had instead already adapted to their losses. I wondered if they had previously been through the same experiences but were further along the same pathway, or whether their sense of normality had been maintained. My feeling is that these ladies had undergone a much more gradual decline, with Mrs Wood's potentially beginning four decades before, following her arthritis diagnosis. Each of these participants was able to find clear links between their self of the past and the self of now as their stories remained integrated with their lives. All but Mrs Ritchie had settled on a clear starting point and cause on which to attribute their circumstances. Normative expectations of ageing did not, alone, seem to suffice as an explanation, yet in combination with other factors could be considered and thus avoid complicity of the self. Such expectations functioned to normalise the older person's situation in terms of their life identity, but also to minimise feelings of being different from others (Kellehear, 2007). Mrs Ritchie, perhaps due to her profound lifelong anxiety and repressive coping style, chose not to think of herself as old or consider, with me, any potential cause for her infirmity, and certainly avoided discussion about what her future may hold. Nevertheless her circumstances made sense to her and she expressed no confusion as to why she was the way she was. All five of these participants managed to continue to live their lives by adapting with attenuated ways of doing and being in order to maintain core values and integrate their sense of self into their current circumstances.

Perhaps buffered by their continuing links with their local communities and social worlds these participants did not lose their sense of belonging to the outside world even when their daily lives were severely restricted. Only Mrs Baxter lacked direct social or community integration yet I understood that that she had never sought to live in this way belonging instead to the tighter social sphere of her close knit family and holding on to this despite geographical separation. Mrs Baxter perhaps illustrated the end of the story where the self is maintained until death. She was the only one of these participants that openly acknowledged her death and anticipated that it would be soon. She revealed no fear of this and indeed almost welcomed it as her life losses accumulated. Even although she may have decided that she would enter the dying role, she did so without an existential death occurring first. For the other participants, there was no explicit acknowledgment of their own death but for Miss Pegg, Mrs Andrew and Mrs Wood neither did this seem particularly feared. What was feared were possible futures of moving to nursing homes, dementia or future illness. Mrs Ritchie's story was the only one where death may have been feared and was expressed via continuing health anxieties described by her daughter. Again, close family members were crucial in enabling the older people to live as they always had done in terms of instrumental assistance but also in legitimising the older person's way of life and supporting them to carry on.

Broadly these stories suggest a trajectory of gradual physical decline and with slightly reducing social connections while the psychological and existential dimensions remained steady, some with a dip in the middle before recovering again as the older people adapted to their circumstances.

6.6.1 Narratives at the personal level:

Maintaining the self: a new normal

Looking to Charmaz's description of loss of self in chronic illness we can see that these participants partially met the conditions required (Charmaz, 1995). They certainly lived a restricted existence, yet managed to work around their restrictions and maintained a degree of choice of valued activities.

Losses of freedom were adjusted to or limited to specific activities. They did not talk about experiences of being discredited, although it may be that they have been subject to such, they were not sensitive to it or did not feel that it applied to themselves. Additionally their self-talk of how they coped allowed self-worth to be maintained (Bury, 2001: 273). Finally they did not describe feelings of social isolation in the way that the previous group of participants did, but maintained social connections and a sense of belonging to the outside world. Even for Mrs Baxter, her concern at being unable to leave the house reflected a frustration at physical confinement rather than social isolation.

These participants appeared to have adapted to their circumstances consistent with Charmaz's stages of adaptation to chronic illness (Charmaz, 1983; Charmaz, 1995). Whilst experiencing and defining impairment, Charmaz explains that bodily changes must be defined and seen as real. Although the older participants did not have a single defining cause for their current frail circumstance their situation made sense to them all. Most offered the objective measurable realities of medical illness or injury, combined with subjective personal and culturally bound realities of aging, to explain the bodily changes and distance the self.

These older people struggled *with* their frail bodies rather than *against* them 'surrendering to the 'sick' self by relinquishing control over illness and flowing with the experience' and in doing so managed to 'integrate new bodily facts into their lives and their self-concepts' (Charmaz, 1995: 663). They managed changing identity goals via attenuated versions of old activities and life roles thus maintaining a valued self. As with the participants in the previous chapter each held a unique and personally located version of what was normal for them. Even although the ability to maintain or regain this normality shifted over the course of the interviews, each was able to live with a newly negotiated version of normal. This was a response shift in the face of physical decline that bolstered self-confidence, sense of personal autonomy and value in the world. Again quoting Charmaz 'as long as an individual feels that he or she exercises choice in valued activities and some freedom of action to pursue these choices, everyday life does not seem so restrictive, suffering is

reduced and self-images maintained.’ (Charmaz, 1983: p172). They did not become defined by their bodily incapacities.

6.6.2 Narratives at the societal level: Stability

At the broader level these were stable core narratives despite the losses that were experienced. The older people managed to retain their sense of belonging in the world. In terms of the morality of these stories, the older people had perhaps moved beyond the evaluative dimension of where they were in their lives by avoiding self-blame, as they were not questioning why they were the way they now were. Experiences of feeling a ‘burden’ were minimised either through offering a degree of reciprocity as described by Bury (Bury, 2001) or a level of self-care that buffered any sense of total dependence.

Chapter 7: The Regressive Narrative: A loosening grip on the self

The following are the stories of George, Mr Mackie, Kathleen, Mr Robson and Mrs Pryor. Kathleen died and Mrs Pryor moved to a care home during the course of the interviews. George and Kathleen lived with their 'frail' spouses, Mr Mackie and Mrs Pryor lived alone supported to varying degrees by younger family members while Mr Robson lived with his son. The stories that these older people told were more diverse in their form than those in the other groups, however the thread that tied them together was the uncertainty and ambiguity, often to the point of anxiety and fear that their stories conveyed. Some showed how they were holding on to or regaining their sense of self, yet how this began to slip away from them again, while Kathleen continued in such a state of flux that prevented any sense of reconstructing her life into a cohesive narrative. The end points of the stories, however, were beginning to meld into those in chapter 5. The participants did not know where their stories were going. In contrast to the participants in chapter 6 who knew where they were and so could live in the now, these older people were almost transfixed by dreaded futures.

7.1 George

It is a worry, it is a worry. When you're old and sick it's a worry.

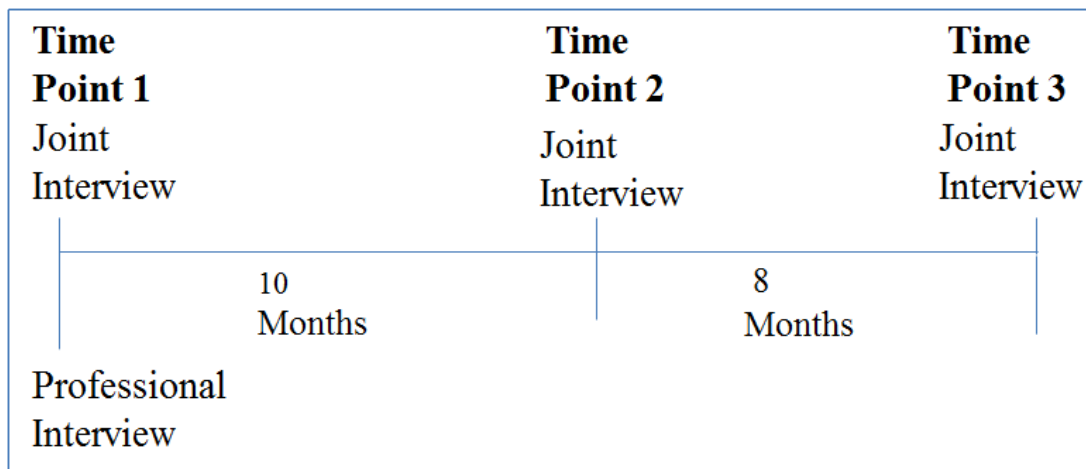


Figure 17. Time line for George

I met with George and his wife Alice three times over a period of 18 months at their home in a sheltered housing complex. George nominated the couple's home carer, Irena, as the formal carer without hesitation at the first interview. She agreed to participate and was interviewed over the telephone shortly afterwards. When I carried out interim telephone calls it was always Alice that answered and while I would hear George chipping in in the background and shouting hello he preferred that I talk to his wife.

Time point one:

George had talked about his wife Alice even when I first met him at the day hospital. His face, although slightly stilted by Parkinson's disease, beamed with pride as he told me how, like all people, I would take to her. I visited their flat in the sheltered accommodation some days later. There were two chairs facing each other, either side of the electric hearth, little tables for eating from, all surrounded by bits and pieces of daily life.. Irena, their Polish care worker, with whom they had formed a close bond, buzzed around coming and going throughout the interview. The couple had no children of their own and joked about adopting Irena and teaching her old Scottish songs and sayings.

George: 'We've got Irina getting acquainted with some of the Scottish sayings.'

Anna: 'Oh have you?'

George: 'She sais 'nae bother at aw''

George and Alice were extremely welcoming and friendly. Alice was as warm, sociable and funny as her husband described, however what I had not expected was that she was disabled with very severe Rheumatoid Arthritis and seemed almost imprisoned in her stiffening and twisting joints. They immediately invited me to use their first names, called me by mine and asked me lots of questions about my own home and family. Alice did most of the talking while George offered humorous interjections, clarifications or occasional disputes of what his wife said but they talked gently to each other coming to a mutual understanding of most issues. George and Alice were colourful and absorbing story tellers and they regaled me with tales from their life together, so entwined that it was impossible to disentangle one from the other. Their world had focused on family and friends and they had a strong sense of community with the area where they had lived and worked since they married. Alice has suffered from Rheumatoid for many years and George had taken physical care of her until he was forced to relinquish this role once his Parkinson's disease progressed.

George had clearly declined physically over recent years however the couple attributed his current circumstances to a fall which had resulted in ongoing pain in George's hip. They were very confused by his level of pain and were not convinced by the diagnosis of a hairline fracture that would self-heal. Unsatisfied they discussed plans to seek a second opinion.

George: 'well I'm not much further forward, I'm still sore (uh huh) I don't' know. I wis gonna try and see the Doctor and see if I could try and see a consultant up at the [hospital] an orthopaedic surgeon.'

Alice: 'an orthopaedic surgeon you know, see if they've got any views on it cos.'

This reduced mobility was difficult for George and a bone of contention between the couple was his refusal to use his wife's electric wheelchair.

Alice: 'Do you know, eh Anna, I've got an electric wheelchair out there (uh huh) and he won't use it (gives me a comical eye roll).'

George: 'ha Hey he hey hey (ho ho) she's good on an electric wheel chair....'

Alice: 'pride's an awfy thing ain't it? (aye (sigh) he'll no use it and abody can get doon the stair and eh.'

George: 'I'm not too sure of it yet Alice, You, you're pretty good at it'

They wished to be out and about more, however Irena and the carers seemed to offer them a link to the outside. George and Alice talked of the current ebb and flow of strangers, aside from Irena, that came from the care agency to help them, from far and wide in the world. They spoke of this with interest, fun and fundamentally in social terms.

George: 'Oh they're all nice'

Alice: 'They're all nice, the Polish lassie they're just nice lassies (Uh hu) whither they're Scottish or Polish whoever they are they're nice lassies (Mm hm) aren't they George?'

George: 'Oh they are aye, aye'

These, the people in their sheltered housing complex as well as old friends, formed their social connections. Irena talked of taking Alice out with her when her shifts had finished describing a genuinely reciprocal sense of care for them. *'I was with I took Alice out after my work finish the other day and we were to be[out]until half past three and it was quarter past five, she is such good fun.'* However she highlighted that George and Alice were unable to go out together and that George could not often join in with Alice's female social activities. George expressed this himself in his desire to try to watch football on television and his longing to, once again, go to matches or local cricket or rugby fixtures hoping still to return to this male orientated aspect of his life.

Alice: 'If he can go to his cricket, it's just along the road. Couldn't he?'

Anna: 'I should think so'

George: 'aye, I'll walk there one of these days'

George's devotion to his football club was clearly a big part of who he was, his home filled with many pieces of club memorabilia and he identified himself as a fan using a colloquial collective term. Both told me of who they believed George really was in terms of a strong and fit self. What I saw before me was not him.

Alice: 'I cannae believe he's like that, a fitter man you couldnae find (Uh hu) I mean even when he retired.'

George: 'I was telling Anna I played football nearly every day.'

George strongly believed that he would get better, become more mobile and get back to his old self *'as I say, I keep hoping this is going to ease and I'll get back to walking again'* however Alice, perhaps more accustomed to physical decline, expressed doubts *'He's always optimistic, I'm no Anna ken I I'm more, I tend to look things square in the face and think, but he's no, he's mister optimistic, he's thinking he's going to get better.'*

George and Alice had experienced many hospital stays however their descriptions of these experiences focused on other patients with dementia, revealing a fear that they too may experience such a fate. *Alice: 'what you think is this a view into the future and what's going to happen to me and that's what upset me more than anything (mm hm) and you know am I going to end up like that'.*

In addition to the fear of dementia was a fear of needing to go into a nursing home perhaps in part because they may be separated.

Alice: 'the warden was saying when we came back from the hospital you know 'you wanting to go into a home' but we ..don't.. want.. to.. do.. that (strongly voiced and punctuated). As long as we can stay in the flat, as long as we can manage'

George: 'oh that's a last resort.'

Alice: 'it's always going to be a last resort (aye) I mean neither he nor I are stupid and I mean we know that place could come one day but that's, we hope we dinnae have to do that eh no?'

George: 'no it's a last resort.'

Alice: 'a last resort.'

George and Alice clearly identified with their selves collectively as a couple both regularly using 'we' to describe their lives. Together they conveyed a sense of being in control of their world and in trying to adapt as best they could, retaining autonomy through their voices as their bodies struggled to function. Staying together in own home and helping each other was vital to them on an existential level as it gave their lives meaning, purpose and continuity with their past. Their main hope was to

continue as they were. *Alice: 'cos it's no charity eh George, it's no charity to accept help, but being together, that's a big thing being in our own wee flat.'*

During the interim phone calls Alice told of her increasing desperation at George's pain as they negotiated appointments and investigations, her voice conveying her distress at witnessing his suffering. I eventually heard that he was to undergo hip replacement surgery so I opted to return five weeks afterwards.

Time point two:

On arrival I found George struggling to mobilise in the wake of the surgery and the interview was infused with an undercurrent of uncertainty and apprehension that I had not perceived before.²³ They told the story of how George came to have his surgery after they had rejected the diagnosis of a hairline fracture and sought a second opinion.

Alice: 'The hip was completely gone, that hip-bone was completely gone'

George: 'You'd think they would have spotted that with all the X-rays that I got'

They spoke repeatedly of the urgent nature of the operation in the context of how long it had taken them to have the situation dealt with revealing a loss of trust in doctors. In the wake of George's post-operative stay, although both George and Alice talked again of other in-patients with dementia, this was not now the focus of their hospital experiences. Instead much of the interview was permeated with tales of nursing mistreatment and medical mistakes, both from a personal and societal perspective. George had returned from hospital now and the trauma of the experience was one that they sought restitution from and to avoid in the future. *Alice: 'Anyway, you're home now, thank god. You don't want to be going back again either.'* Their insecurity was exacerbated by the economic crisis faced by the country and George and Alice discussed it at length expressing a new sense of powerlessness and fear for the future.

²³ I was so looking forward to seeing George and Alice again. They were just so flat and dejected. Was I expecting too much? Were they used to me so no need for a performance? It is the negativity though that is really new I think. I feel really flat.

Alice: 'Well, if they decide to do away with [the attendance allowance], what can you do, Anna? You know, you're a captive audience, you can't run away. If somebody makes that decision (uh-huh) we'll have to go with it, won't we?'

Despite Alice's sense of insecurity with the outside world making her increasingly reluctant to leave the house, George remained hopeful that his mobility would improve and he would be able to get out more again *'Och aye, as the weather gets better we're hoping to get out a bit more.'* Returning to this 'normality' in order to attend local sporting events and to look after Alice was important in that it was tied to his masculine sense of self and a link to the person he felt he was.

Alice: 'He was the one that went to it all the time, I was the one that was never bothered about the one that he went to.'

George: 'I used to go along and watch the cricket at the [local cricket club]...'

Alice: 'And then the rugby.'

George: '...and the rugby at [local rugby club].'

Alice: 'He used to do a lot of shopping, didn't you, around the place for me too, didn't you?'

George: 'Aye, yeah I did.'

That this was not the 'real' George was again reiterated by both parties as Alice reminded me *'before this all happened to him, he was a big strong fellow, you know'*. George even offered rationalisations of ways that he was trying to still be this person by diverting the focus away from his mobility impairment *'Aye, strong... well, the upper torso's strong, that's it, strong arms and everything else.'* Accordingly he was keen to go back to the day hospital for physiotherapy *'So I'm waiting on word... I think I'll get word that I've to attend the day centre for physiotherapy again.'* He was hopeful that physiotherapy would aid his recovery. He felt that he could get back to being strong: to being him albeit an attenuated version.

Alice: 'Just get him walking right, that's all.'

George: 'Aye, just getting better.'

Alice: 'Getting better, that's all we want.'

George: 'And I'd like to go out walking unaided.'

Alice: 'Even if it was walking with a stick but as long as you're walking properly, even with a stick.'

George: 'Aye, even with a stick, aye.'

Alice: 'I don't want you to be Linford bloody Christie, I just want you to get better, that's all. That's the one thing, nothing else, I'd be happy.'

Their home was where they felt safe and looked after, yet their social connections seemed to be reduced as they offered much less in terms of social activity. That George was clearly missing male company was evident in how he relished the manly banter with the ambulance men on trips to the day hospital.

George: 'I enjoy the drive in the ambulances, which may sound sort of funny, but when the ambulance comes for me and we sometimes go and pick up two or three other people (uh-huh), I enjoy the drive!'

Alice: 'The boy took you for a run one day, didn't he? The boy took you for a run one day in the ambulance, he said "would you like to come with us?"'

George: 'I got to know the ambulance men very well, eh?'

However their bond with Irina remained as strong as ever and I began to take more seriously the older couple's jokes about adopting her. It seemed to me that this bond was vital and was one that George and Alice were doing everything they could to maintain given that Irina's position as an agency carer lent a precarious nature to her involvement with them. The existential importance to George and Alice's sense of togetherness and of looking after each other remained however. Alice told me *'You know this – I'm not just saying this because he's happy with me – but we're quite contented souls, ken what I mean?'*

Although they seemed to have come to terms with their circumstances, Alice described the inherent struggle in the process of getting to this stage. *Alice: 'we didnae want it and he particularly didnae want it but it was a big step to do that and we accept now we cannae do without the help so dinnae be proud, take the help and make your life easier and you've got time to sit and enjoy each other's company. Accept all the help that you're given.'* It was here that I noticed that they talked

more about their daily routines where Alice listened to audio books and George watched sport on the laptop that perhaps offered a sense of security and normality.

Time point three:

George's recovery continued slowly and I saw them for the last time in the depths of a brutal winter with national 'austerity measures' in progress. George was markedly quieter and more disengaged with the jokes and 'bonhomie' now almost absent.²⁴ George's hip replacement was now nine months in the past and while he had recovered and no longer had pain he had not regained mobility to the extent that he had hoped. George's main physical focus had now shifted to his Parkinson's disease for which he had increased his medication. Alice, perhaps sensing her husband becoming weaker, seemed to be taking charge a bit more.

George had been going back to the day hospital and Alice was aware of the social benefit for him '*But he likes going there, I like him to go because ... I mean, he's with me all the time, you know, and I know I'm a scintillating conversationalist but...*' while George pipped in '*I got a laugh with the ambulance... the ambulance drivers are funny, eh*'.

George's social world had diminished as the only male company he described was through these ambulance drivers. He seemed sadly to have accepted this as he had given up his yearning to attend sporting events and no longer talked of wanting to go out and about. Irena continued as the main agency carer and she and her boyfriend spent part of Christmas with the older couple, the bond becoming increasingly strong. This offered a cushion to the social losses of the older couple. Although the couple's social world continued to centre around the sheltered housing complex and Alice described people popping in regularly to visit this was less evident than previously. They certainly talked less about the others in their world and had chosen not to attend the Christmas party in their building.

²⁴ Field Note: It is stunning today. They were both so interested in asking about me before but not at all this time. They said that they'd enjoyed my visits and I'd been very nice but they just seem much more inwardly focused generally. Sadder. More defeated?

A sense of hopelessness had entered their story with George seemingly more resigned to his ever reducing mobility and no longer voicing hopes for improvement. Their previous capacity to control their world via their 'voice' since their physical selves were declining seemed threatened as they felt powerless to influence their future. *Alice: 'if they make decisions for you you've got to agree with them.'* It was a situation that seemed more like giving up than accepting, as George struggled to find any meaningful way to integrate his current situation with his sense of self or his life story, no longer offering an old 'real' self, barely talking of himself at all. Neither did he explain his reduced mobility in terms of Parkinson's' Disease. Although they thought of the future, at no time did they talk of George's life ending. Instead, having increased their personal care package to the maximum and made further adaptations to their home, they relayed an abject fear of what may lie ahead. This fear increased over the period of the interviews and centred on the possibility of a nursing home. The notion that they should consider a nursing home was resisted strongly as Alice described *'[the warden of the sheltered housing] says "you'll maybe need to think about going in a home" – "not if I can help it." 'I don't like the sound of a home, do we George?'* and George agreed *'No, it's a last resort.'* They both talked of visiting people in nursing homes to explain their dread.

George: '[residents are] ...just sitting round... just sitting in rows, eh?'

Alice: 'Well, we'd have to say it's the preconceived ideas we've got about nursing homes, it frightens the life out of us' 'I've just got a horror of it, Anna, I've got a real horror of it, both of us, I really have.'

Again, George nodded his agreement. The existential value to them of staying together in their own home was a constant that offered meaning and purpose in life and a nursing home would threaten not only this, *'I don't want to do that, I want to stay in my own home, we do'* but also the one remaining function of self that George seemed to hold on to, of helping his wife. He smiled and nodded proudly as his wife described how much he did *'I mean, he does a lot, he does a lot, he really does. He makes the breakfast for me, I come through and that, Anna, and he makes my breakfast.'*

7.1.1 Concluding George's story

The beginning of the story for George and his wife was initially attributed to the hip fracture which they had struggled to have diagnosed. George subsequently sought restitution following his surgery and willed himself to return to a physically strong self and to be able to walk well again. When this failed to happen George's pre-existing Parkinson's disease provided a new focus for him yet in itself did not seem to mitigate against the loss to his sense of who he was. George sought to ameliorate the losses to his lifelong male roles by enjoying the male company of ambulance drivers and following sport in what ways he could, however the loss of his sense of self as someone who was physically strong seemed overpowering. Although the couple had initially adapted to their circumstances, in the face of a diminished capacity to influence their world through their voiced insistences, they began to lose their optimism and turned inwards away from the outside world. Neither George nor Alice voiced consideration of their death. The future event that they feared and dreaded was a potential move to a nursing home; a fate worse than death signifying to them an end to their story. Their lives seemed precariously balanced on a precipice where existential comfort was garnered from staying together in the confines of their small home, propped up by the moral and physical support of Irina. I feared for them that the smallest issue would force them out of their house, into a care home where I felt they would existentially struggle. Our final meeting ended with Alice showing me a photo of her and George when they were young, beaming and smiling out of the frame, their youthful selves looking to their future. It struck me as a poignant gesture that acted as a coda summing up the very essence of their story of their life together in sad contrast to their fears for the future.

'Oh, the future, we've got no future, it's in other people's hands now, we know that.'

7.2 Mr Mackie

'We have an excellent relationship really, my you people are very, very good.'

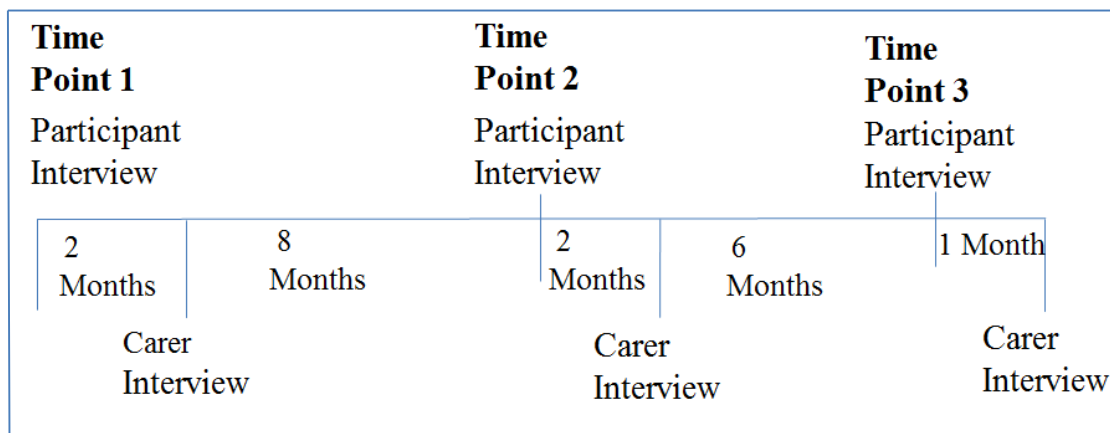


Figure 18. Time line for Mr Mackie

Mr Mackie talked of his grandchildren the very first time that I met him in the day hospital. He was proud of and delighted by his ongoing close relationship with these young adults and the theme repeated across all times that we met. He lived alone in the home, in the small town, that he had shared with his wife who had died over 20 years ago. His daughter and grandchildren lived some 20 miles away and although his daughter talked of her brother, this son was only once mentioned to me by Mr Mackie²⁵. His occupation had been business and local council orientated and he had been a keen athlete to regional standard in his youth. I visited him in his home and his daughter in hers on three occasions each over the course of 18 months to 2 years, allowing for a period of hospital stay where our interview was delayed and I awaited his return from hospital. When I did contact Mr Mackie for interim phone calls he asked that I visit him instead. Thus I visited Mr Mackie on two occasions for 30 minutes each time to evaluate his situation and consider when to plan a follow up interview. Mr Mackie nominated his GP as a professional carer and then his agency home carer when the GP declined to take part. Unfortunately while the home carer

²⁵ As an only daughter with two brothers I may be focusing on the role of daughters both during the interviews and in the analysis.

agreed to participate in the study, she subsequently did not arrive at the arranged meeting place and did not respond to further attempts to contact her.

Time point one:

Mr Mackie was a tall, strong looking man who sat with poise in his easy chair in the south facing dining room of his home, looking out onto his garden. He was smart and spoke confidently yet softly and reflectively about his life. Despite his frailty and great difficulty in mobilising, he looked younger than his years and deceptively fit, such that I struggled to shake the sense that I expected him to be able to stride easily around the room. Mr Mackie described a starting point, as opposed to an event, to the story of his current situation, talking of his reducing mobility as an unnamed 'it'. *'I mean looking back it sounds silly but the first time I really suffered from it I was on holiday in Austria in Vienna. Now I used to be in the local light opera company in [Place Name] and when we did musical plays and there was any waltzing and so on the young folks had no idea of the circle waltz or that at all and they used to, I used to get dug out. So when we were in Vienna they did a little show for us, a light opera and then they announced that there would be dancing afterwards and I got up and I thought this is wonderful after all this time I'll waltz in Vienna and I found myself staggering and I just couldn't get my legs working properly and that was quite a few years ago'.* It was from this point on that he had become less physically able and now walked minimally and unsteadily with a walking frame, relying on help from carers each day to manage his life.

When Mr Mackie spoke of his current life and the assistance he received he used consumerist language which allowed him to position himself with some power as someone 'buying' care rather than being a needy recipient yet omitted any personal pronoun from such statements *'No, as I say if you can have one satisfied customer'*. In evaluating these services he was careful to express gratitude for the help he received.

Mr Mackie: 'I can't honestly think of any reason for complaint and I can't really think of anything that I could expect more.'

Anna: 'Well that's a nice position then to be in.'

Mr Mackie: 'One satisfied customer.'

His sense of self was, however, contradictory, suggesting a struggle to accept his current situation and increasing dependence. On the one hand he would defer to realistic rationalisations and offer normative explanations *'I don't expect to get new legs at 91, I mean you've got to be realistic'* then would express frustration *'Well [physio] does her best, I'm not a damn bit better than I was'* and offer a more comforting, resisting statement *'you don't give up, it's as simple as that'*. His daughter, Gill, described her father's path of resistance in the face of his decline. *'He's fought every inch of the way when he needed a walking stick at first he didn't want one (uh huh) you know, every aid he's not wanted but he, with him you've just got to let him, you've not to force him, you've just got to wait until it comes from him, you know you can implant an idea (mm mhm) in his head and leave it and he likes it to come as then coming from him.'* Despite his declarations of satisfaction the frustration of his situation permeated the interview, *'I mean unfortunately you can't give me new legs. If I was just better at my walking I would be perfectly alright and I'm not going to get better at my walking despite what [physio]'*. He focused on the forced inactivity, dependence and inability to do what he could before *'If I'm sitting on my bottom not doing anything I just don't feel terribly different at all but of course when I get on my legs it's frustrating. I suffer more from frustration than anything else really. I mean I sit and look at the garden, on a nice day I could be out working about on it. This of course is a good idea because I can open this door wide, I don't have to go out. It's just as I say I do appreciate I could be an awful lot worse off but the little things that go wrong that I can't fix. If that bulb blew I can't get up I've got to wait till somebody comes to change a bulb, it's these little things that really frustrate you.'*

His old self was one that 'could' yet now he could not. His new found restricted existence was highlighted by his choice to wistfully recount tales from the period of his life, his early 20s as a soldier training in England with a motor cycle platoon. Mr Mackie had moments when his sense of self regained agency over passivity and these were in interactions with his family. It was here where his use of personal pronouns changed and he spoke of 'we': *'we have an excellent relationship really, my young people are very, very good,'* his daughter doing the same. *'You know the kids have*

been brought up with him (uh huh) but I think at the same time because he's interested in them (yes), supportive but not you know too much so that they just really, they're very, very fond of him, you know what I mean, they (mm mhm), they would just do anything for him.'

Mr Mackie's grandchildren were very close to him having organised a rota where one would call or visit each day, often requiring multiple bus trips from far across the city, and had installed a phone in every room enabling him to always be in a position to answer. His pride and delight in these young people was evident and was what he told me about at our first meeting at the day hospital. His daughter similarly told me of her children's devotion to their grandfather, explaining how following the death of his wife Mr Mackie had become very involved with the young family, and had remained closely interested in them and their lives. She felt that he deserved their devotion and it was touching to hear. It was his family that formed his social bonds and enabled him to carry out the small acts that could allow him to maintain a modicum of independence and continue with social conventions. *'Usually on a Sunday one of the members comes across for me and I go up for tea on a Sunday and sometimes for instance I may get one of them to take me up, I always like to buy my own Christmas cards and they'll possibly take, I've got the wheelchair round there, they'll maybe take me up to the [shopping centre] to have a look at something like that but I can't go out on my own.'* With his family, it seemed that he could still be him as he always had, and he still listened, advised and was treated with respect. Gill: *'Well they are good to him, they are very good to him, uh huh (yeah he's), and I think that, it does keep him going.'*

Mr Mackie had thought about his future and was philosophical about his life expectancy yet did not consider death as imminent *'I'd just like to see the next few years, I may or may not. I'm quite philosophical about it, I mean let's face it you can't last for ever and if I went downhill a lot more I wouldn't want to be carrying on and just being a nuisance to everybody so I mean I think I'm reasonably philosophical about it'*. However with respect to how he thought about how he would die he expressed his desire for a sudden death *'I don't wish to be morbid but*

I've had three sets of friends in the past who funnily enough all just popped off in their sleep, fairly well on in years and that's all I would ask for eventually.' Beyond this he talked of the future only in terms of what he wished to avoid. The first was borne out of his experiences of being in hospital. *'I mean the last time, not the [Hospital1], the [Hospital1] is nice but the last time I was in the [Hospital2] it was horrendous, it really was. I had a urinary infection and I've never been so disgusted by a hospital as with the attitude of the [Hospital2]. The staff beefed, they were moaning their heads off, if you pressed buzzers in the night, not that I did but I was in a wee ward for six and two of us were reasonably compos mentis, the other four were definitely having problems and were shouting the odds in the middle of the night. If you pressed the bell you could press to your heart's content and nobody would come, they would sit out, the nurses would sit out in the corridor beefing about their conditions of pay, service and what have you. I was appalled, I mean I'd always had the impression rightly or wrongly that nurses were sort of a bit better than that, caring sort of people.'* These experiences has shocked him, violated his trust in nursing care leading to a fear of a neglected demise in a general hospital *'No, and for God's sake let me pop off suddenly and not come back here because I would hate to be left like that.'*

Mr Mackie similarly feared dementia, peppering the interview with statements such as *'so long as I just don't go ga-ga'* while Gill expressed her father views on going into a nursing home *'I know that if we put him into a home that'd be the end, I could, you know what I mean, it really would be, he just would hate it (mm mhm) so I mean that would be a very, very last resort'* as a fate worse than death *'he's always said oh don't put me into a home shoot me first'*.

However, that Mr Mackie also retained some hope for his future was evident in his discussions about physiotherapy at the Day Hospital, which he felt offered the potential if not for improvement at least to prevent further loss of his mobility. *'It's not easy but I force myself to do it. I don't know if you know [physio] the physiotherapist at the [Hospital1] but [physio] is a bit of a dragon, you know, she means well so like if you don't use it you'll lose it, so I do make a point of just getting about the house doing things.'* This offered a sense of retaining some control in his

world by doing so *'My walking is not improving and I don't suppose it will but that is really quite helpful and so long as I can dot around the house I'll stick it out.'*

Ultimately it was the company of his daughter and grandchildren that Mr Mackie prized above all else *'But as I say there's hardly a day goes past that one or other doesn't give me a ring to see what's happening or two of them drive so they can pop out with the car and the third one he drives but he borrows, the family got the insurance covered for the family car so he in fact on Sunday, yesterday my daughter came across for me but [grandson] drove me home'* and was described in terms of existential importance by Gill *'well they are all very good to him, they are very good to him, uh huh, and I think that it does keep him going.'*

Time point two:

In the intervening months Mr Mackie's physical weakness had increased and he was briefly hospitalised with an episode of shingles. Mr Mackie struggled further with deteriorating eyesight which was a significant issue because of the impact on his routine.

Anna: 'But his loss of reading through his eyesight, that's.....'

Gill: 'It's a big thing, mm-hm. Because he used to go through three books a week, you know, and his Observer, his this and that.'

Mr Mackie had structured his days spending the morning in his back room facing the garden reading the newspapers, books in the afternoon and moving through to his front room to watch television in the evening. Having faced the loss of other activities, *'I had a fair mixture of hobbies and so on that it always kept me going. This is how, you know, I feel terrible, stuck now'* being unable to read rendered him unoccupied and bored and frustrated in the day *'You get bored day after day just sitting here you know'*. He no longer used the 'satisfied customer' line and now complained more openly albeit in a distanced manner about how he felt *'oh you get your down days, you can't avoid it'* and about his deteriorating physical condition *'oh getting about is just hopeless'*. I considered that he may be offering a more private account to me at the second interview, however Gill told me how he was more unsettled and anxious than previously: *'he's just not what he was like before,*

you know. I think because he's got nothing better to do he worries about everything' describing her father as exhibiting an uncharacteristically short temper. *'But of course, he just [snaps fingers] expects me to do it like that! But I think that must be age, just... because he's got nothing else to think about and he worries about everything now.'*

Mr Mackie's physical deterioration had continued to the point that he needed his family's help to physically get out of the house and Gill talked of her father's unwillingness to accept his decline *'I think he knows that deep down, he just gets really frustrated with the situation'* and shame regarding his current situation. She told of how he had refused increased personal care to the detriment of personal hygiene and further refused to have an adapted toilet installed in the downstairs bathroom because of the public image that adaptation would convey to visitors. However Mr Mackie's own account revealed a dissonance between the generational moral imperative to be stoical *'I know I'm luckier than most. As I say the family are very good.'* and his frustration *'I mean actually of all my problems frustration is the main one, just not being able to do things.'*

His family continued to offer scaffolding by striving to ensure that Mr Mackie maintained a degree of independence and say in his own life *'you've just got to let him, you've not to force him, you've just got to wait until it comes from him you know'*. Although Mr Mackie's close relationships with his grandchildren and daughter brought much comfort to him his social isolation was becoming more of a concern for Gill and was clear in his expression to me. *'I've been chuntering on there to you but it's nice to have your company because even with all the youngsters coming in, it's nice to have someone....'* Despite his reluctance, Gill had enrolled her father at a day centre in the hope that he would enjoy the social interaction with others near his own age *'He said [about the day centre] "(sigh) I mean, bingo's just not for me" and I said "well, give it a chance, Dad" but I know he just didn't like it.'* It became clear to me at the second interview that Mr Mackie's grandchildren not only brought social interaction and familial bonds but that they engendered a feeling of being valued and of belonging in the world. *'I'm very lucky the youngsters come*

out and they do their...Well, they're always doing something so I'm always interested in what they're doing, they don't make me feel out of it as you might say.'

In contrast Mr Mackie expressed his dismay at the ageist and demeaning attitude of a surgeon to whom he had been referred for his abdominal bloating.

Mr Mackie: 'he was rude andoh I mean, he just got my back up right from the start, you know.'

Anna: 'What was it he said again, you told me when I saw you in between?'

Mr Mackie: 'Aye, he told me that, erm...he was complaining about he wouldn't do anybody at my age for a start and was complaining about the GPs who keep sending people when they know perfectly well that he wouldn't do anything about it and he said "if you come back and it's another six months you'll just be wasting your time and mine."'²⁶

Time point three:

By the time I met Mr Mackie for the third time he complained of increasing tiredness and declining eyesight and mobility *'and without the walking frame I couldn't walk over...'* yet seemed to have come to accept his situation.

Anna: 'I'm trying to remember when I first came to see you, when I first met you, do you think it's a change you feel now that you won't ever walk again, do you think that's something that's changed in your own mind or.....?'

Mr Mackie: 'Och, I mean.....'

Anna: 'Have you been thinking that for a long time?'

Mr Mackie: 'I made the point, I've accepted that now for quite a long time.'

However he now expressed frustration at feeling infantilised by personal care. *'Och no, I mean, it's bad enough being treating like a baby in many cases during the day, I don't want to be put to bed!'* This was not a criticism of his carers but of the very nature of having personal physical care and, as alluded to by his daughter previously, he was at the limit of tolerable dependence on others. It was at this final interview

²⁶ I was furious about this story. I could not believe that any health care professional could be so demeaning.

that Mr Mackie's sense of old and new self was again evident in his tendency to talk about his younger self focusing on his sporting achievements and regaling me with tales of this period of life and again of his days in the army. It seemed that doing so allowed him to tell me again of who he felt he really was and to comfort himself in the process after much discussion of his difficulties.

Mr Mackie's social world remained limited to his family and to his carers with whom he had formed a bond. Gill: *'he likes his carer, the care system, particularly one [carer], he's (yeah)....you know, he really sort of leans towards her. I think it's nice that they've got a little group, it's not somebody different if he....'* Beyond this his evaluation of his social world was more negative as he described the loss of his friends: *'there's nobody left'*. Also his trial at the local day centre had not been successful *'it wasn't for me.'* As he explained, *'the people were very nice, the [day centre] people were very nice, they did their best but you're sort of sitting in a circle and doing bingo and so forth like.'* However, Mr Mackie's burgeoning shame at his situation continued as highlighted by Gill's description of her father's newfound comfort at visiting the garden centre where he did not feel conspicuous.

Gill: *'I take him along to the garden centre, he likes going there for a coffee and...'*

Anna: *'Yeah.'*

Gill: *'I think that's stress-free because there's old people there and, you know, he probably doesn't feel conspicuous.'*

Anna: *'Yeah, do you think he feels conspicuous when he's other places?'*

Gill: *'Probably a bit. I suppose, you know, just...'*

Primarily Mr Mackie's account now expressed openness about not wishing to belong in the world as an old, possibly frail person as he distanced himself from other older people and expressed the distress he felt in their company. *'I mean, I still... as I say, it sounds ridiculous but like the [name of day centre], I feel so many of these folks are old folks, they're old folks mentally and I don't feel old mentally,'* and his feeling that he wasn't old. Gill: *'you see he doesn't think he's old, do you know what I mean? Well he does know it but you know what I mean. When he sees a lot of old people just sitting there I don't think it does anything for him!'*

Thus the importance of Mr Mackie's grandchildren became clear. His sense of belonging in the world was tied to his relationship with them as they allowed him to still feel valued and continue to be himself. Also they became ever more vital to Mr Mackie's existential wellbeing as time went on and his world began to close in.

However, Mr Mackie had now given up hope of delaying physical decline *'I know that I'm not going to be able to walk again...'* and his discharge from the day hospital offered him what he believed was objective evidence to back up his view.

Mr Mackie: 'I mean, the [name of hospital] have given up on me! Last time I was there, when they finished they said I wasn't required back again (laughs), they've put it in writing, so...!'

Anna: 'Oh, that's a shame because you went there for a few bouts, didn't you?'

Mr Mackie: 'Aye, over a year or two I had two or three... usually it was a question of six sessions but I suppose they realised that they were not getting any strength in my legs now'. Mr Mackie now reiterated his earlier normative explanations of deterioration with age 'After all, it's... (laughs), it's just a gradual deterioration, you can't expect anything else.' I began to notice a subtle difference in how he talked about his circumstances, as despite these explanations he still strove to understand why he was so incapacitated. *'I'm just curious as to why your body...and apparently it looks alright as it were, and yet it just doesn't work'* when he had no overarching attributing symptoms or diagnosis. *'It's weakness, it's not sore, it's not stiffness or sore, I mean, there's no.....you know'*

His focus of hope was now to improve his sight. *'I'm reasonably contented with what's been done for me and if I could just get, as I say, a bit of improvement to my eyesight that would enable me to read I would be quite happy.'*

Mr Mackie talked openly about the likelihood that he could soon die yet shared no fear of death but rather of what he may become. He repeatedly voiced fears of burdening his family. *'I mean, it is a bit of a struggle at times and I couldn't let the family down. (Uh-huh...)But, er... I've had a long life and a good one and life doesn't owe me anything so I mean, if I'm going to have to call it a day I might as well call it a day while I'm still happily remembered and not a burden on the family or anything like that'.* He also considered admission to a nursing home a fate that

would make life pointless *'I mean the day may come when I can't look after myself and I certainly don't want to be landed on the family at that stage. So I mean, if I was..(laughs) if the day came that I wasn't able to look after myself but I was still compos mentis then I suppose I might have to do something like [move to a care home] but I don't think I'd take kindly to it.'*

Anna: *'No. what do you think would be the most difficult thing to adjust to if that was ever....? I'm not saying that you would ever, just.....'*

Mr Mackie: *'Och....I don't know, it's just.....I think....I would give up the struggle, quite honestly'*

Moving to a nursing home signalled, for him, a terminal state *'I mean in hospital you know you're going to get out, you hope you're going to get out. (Uh huh) I mean, to go into a nursing home now at my stage, it's just sort of the last lap (laughs) I would reckon there's no use in prolonging the agony really.'* This was reiterated in detail by Gill *'If you put him in a care home he'd be sitting with old people, He would just.....it would just be the end for him'*. The only future he would consider would be to die in his sleep *'I would like to just think that one day I'll pop off and that'll be it'*. Life for Mr Mackie seemed to become simply an ever increasing struggle encapsulated in his metaphor *'I just soldier on'*.

7.2.1 Concluding Mr Mackie's story

Mr Mackie's story had begun with the starting point when he noticed his weakening physical state. He expressed his frustration yet strove to accept how he was. While initially hoping to stall his decline this hope was lost as time went by. Mr Mackie managed to hold on to his sense of who he was through his relationship with his grandchildren who enabled him to feel that he belonged and was valued in the world as he was able to remain engaged in their lives and reciprocate in the relationship by listening to and advising them. Yet this was threatened as he could not tolerate what he perceived as becoming a burden to them, should his physical dependency increase yet further. Thus the hold on his sense of self was beginning to loosen evident in feelings of shame, of being infantilised and increasing fears and anxieties of the

future. While death itself was not feared, the implications of increasing deterioration was an ending that seemed to be a fate worse than death.

7.3 Kathleen

'Look, please tell us what's going on, what's the prognosis because we've failed to get a proper prognosis.'

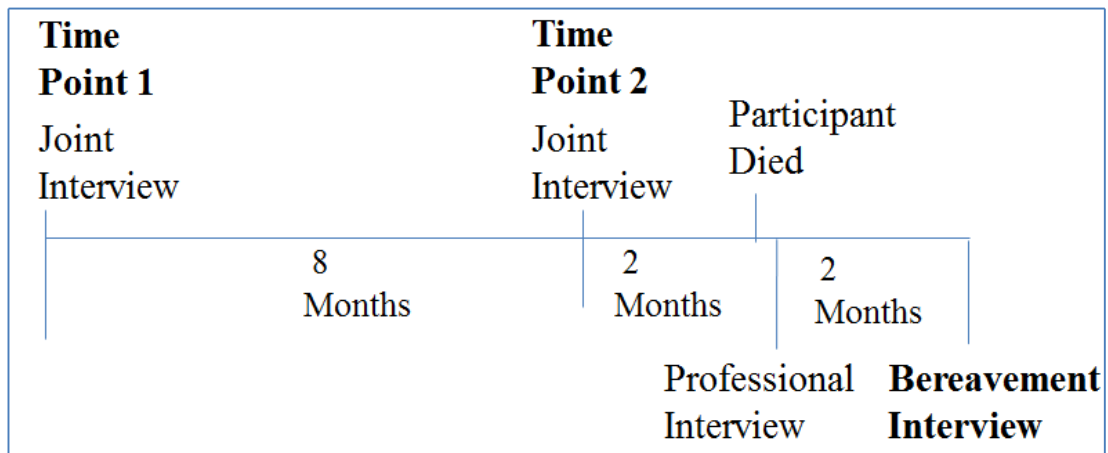


Figure 19. Time line for Kathleen

I met with Kathleen and her husband Robert jointly at their home on two occasions with eight months apart. At the second interview Kathleen was able to nominate their GP as a professional carer whom I was able to interview two months later. It was here that I heard that Kathleen had died the previous weekend. I carried out a bereavement interview with Robert some weeks following Kathleen's death.

Kathleen lived with her husband Robert in a modern linked house in a quiet leafy street to where they had 'downsized' after they had retired. They had grownup children, the nearest of whom lived on the other side of the country. Kathleen had given up work when she had become a mother while Robert had worked in a high status profession.

Time point one:

Kathleen and Robert each had their seat in the living room which was open plan to the dining and kitchen area. Tall and thin, Robert bumbled up and down, often walking in a precarious 'yaw', during the interview as he attended to various needs, while Kathleen remained seated with her legs elevated on a stool and spoke gently.

They were warm and welcoming and spoke almost as one, their views never conflicting, and asked a lot about me, about my family and showing great interest in my work.

Although Kathleen and Robert told me the story of their lives when we first met, the story of Kathleen's current difficulties began with a stroke, offering a starting point for her physical decline. Her story was now one of striving for restitution to her difficulties, which focused on increasing symptoms of pain and physical weakness. In addition to the stroke Kathleen did offer old age as an explanation for how she found herself *'of course it's old age anyway, I would not have been able to do as much'*, however, neither factor provided a satisfactory explanation and their story was dominated by a search for answers. Kathleen's mobility had declined and she experienced on-going pain in her feet which, despite the couple's quest to overcome this by trialling different combinations of medications, remained inadequately controlled. However their GP told of her difficulties in helping Kathleen manage her pain. *'I got slightly frustrated cause I would be offering lots of suggestions and ideas and she would try them briefly and then move on, and especially around pain management'* as was similarly described by Kathleen: *'I've tried that it doesn't work, I've tried one and it made me dizzy, you know, I don't like what the bit of paper says about this drug'*. Robert described their plans to see medical staff: *'Kathleen is very, very worried about the, the occurrence of pain which is going on and on. She's made an appointment to see [GP] who is the senior practitioner next Tuesday which, you know, it could have been yesterday from our point of view but that's as soon as we can be seen, so she's going to be seen then with a view to saying look please tell us what's going on, what's the prognosis because we have failed to get a proper diagnosis'*. Their doctors' inability to diagnose a cause seemed to mean to both Kathleen and Robert that a cause had yet to be found.

The GP also described a circular process of answer seeking where Kathleen would push for referrals to secondary care to have her symptoms investigated yet return without an answer and would start the process all over again *'So kept coming back to, to more solutions but obviously at some points you then refer to a pain clinic and get some management ideas which actually are the things that I've already tried, and*

we try and go round them all again. Em so and one of my colleagues saw her two weeks, started the whole process again.'

In herself Kathleen was calm and quietly spoken yet described her frustration at not being able to 'do' things herself. Her physical self was described in terms of loss with many 'I can't' statements *'I used to go a walk every afternoon but I can't do it now' 'standing I can't do very well, chopping up veg and things. I'm sorry about it because I liked cooking'* yet when she and Robert talked about their capacity to manage their lives they expressed a sense of autonomy as they solved the problems that they faced in whatever ways they could such as purchasing ready meals. Robert: *'I can make omelettes and eggs, bacon and egg but things and things that are fit for the bin properly so we go to a company called Wiltshire'* and having agency carers in to help Kathleen: *'There's an endless stream of carers come along'* and in supporting each other as Robert explained *'I try to express things formally but if you want to ask what the sentiment is, what we hope to do I've just told you, support each other.'*

The couple remained socially connected to the community and talked positively of their neighbours *'They're loaded with kindness, people are very, very helpful, neighbours are good'* who were supportive to the older couple. They also described a close relationship with their children who were now scattered over the country. Yet considering their place in society more broadly there were implications that they considered older adults to be a societal burden as they talked of media reports of old people generally *'Well there's so many of us, it's frightening and getting worse and worse apparently, in the newspaper it says anyway.'* Consistent with this was how they considered my interview with them to be almost a privilege.

Kathleen 'It's nice to have someone you can talk to'

Anna 'Well I hope so'

Kathleen 'Because I mean you feel you're imposing on most people'

Kathleen and Robert propped each other up in every way possible presenting themselves as a joint force in their narrative as they faced difficulties together. This,

along with their strong Christian faith and their family gave their lives meaning and purpose. They were able to attend an afternoon church service followed by a lunch, arranged for older people that may not manage a full Sunday event and were deeply grateful for the provision socially and spiritually. *'About 30 or 40 people arrive at the church and we have a service of half an hour and then we have lunch together, soup and a roll, cheese and butter and whatnot and a chat so that's a very good social as well as a, it's a profound religious experience as well.'*

Looking to the future the couple explicitly talked of their lives nearing their end. *Robert: 'Well we're both in our 80s, well I'm 85 and Kathleen is 84, we don't really have statistically great expectations of life you see, sorry but you have to face it.'* Yet death remained abstract and distant and they expected their lives to continue for the next few years. *Robert: 'if it is Parkinson's disease there is no cure, there's palliative treatment and it can be good for another four or five years at least.'* The couple maintained hope in wishing for an improvement in Kathleen's health but their main hope for the future was to stay where they were, in their own house and to support each other. There was, however, a worst case scenario that they wished to avoid at all costs which was to go to a Nursing home. *'We'll do almost anything short of A-bankruptcy or B-going into a home'*

Time point two:

In the intervening months Kathleen's weakness and tiredness continued. The couple continued to strive to adapt and cope and had installed a stair lift, however the pain in Kathleen's feet became increasingly distressing particularly overnight. The couple still sought different combinations of analgesics to alleviate this pain yet Kathleen felt unable to tolerate side effects of many medicines. Their further quest for a diagnosis resulted in the hypothesis of Parkinson's disease being ruled out which, while reassuring, the lack of an explanation left Kathleen with a feeling of rejection.

Robert: 'They decided after nearly six months that it WAS NOT Parkinson's disease...'

Kathleen: So that was a big plus.'

Robert: '.....so they stopped treating.....the drugs for that and we have made no progress nor have we gone backwards so things are static'

Anna: 'OK'

Robert: 'that's the brief situation'

Kathleen 'I often feel they've sort of kind of written me off and said "well, there's nothing much more we can do."'

This sense of feeling 'written off' extended to health services generally as her annunciation of the word 'they' made it clear that she did not just mean the day hospital.

Anna: 'OK so you feel maybe a bit written off by....is that by the [day hospital]?'

*Kathleen: 'oh **they** wrote me off yes! (laughs). I liked going, it was nice.'*

Although they continued to strive for a return to 'normal' there was a degree of acceptance beginning to emerge as they openly discussed Kathleen's deterioration. However this was accompanied by a level of difficulty in adjusting evident in the distanced almost disembodied language used to describe her difficulties.

Robert: 'There's been a weight loss'

Anna: 'OK'

Kathleen: 'Yes I began to find that'

Robert: 'And there's been certainly depreciation in mobility'

Accompanying this was a new sense of life having changed evident in their decision to discard their evening clothes. *'You know, evening dresses that I used to wear for conferences and things. I'm obviously never going to wear them,'* with an accompanying lamenting of the passing of life stages *'Oh well, it's a bit of a wrench and that's what Kathleen's been going through yesterday, parting with all these nice things.'*

Anna: 'Yes, it must be quite a wrench, I can see that by your...'

Robert: 'Mm.'

Kathleen: 'Well, they all have memories, don't they.'

They also lamented the loss of activities they considered as part of their stage of life.

Kathleen: 'Creating things and you can knit or sew and things'

Robert: 'You are deprived of doing things'

The couple also struggled with the nature of care that was necessary and felt that they were at the limit of what they could tolerate.

Kathleen: 'Well, I get a lot of help, I must say. But your life's not your own, you know, when you're waiting for somebody to come to dress you and things. You leave your modesty outside! (laughs). So I think they're all very helpful. I don't know what else they can do.'

Robert: 'I think we have as much secular, physical help as we can handle.'

They now also described struggling with low moods.

Kathleen: 'He gets a bit down sometimes.'

Robert: 'And I do have times when I get very depressed.'

Kathleen: 'I don't know why, I mean, there's no particular reason.'

Robert: 'But I know it, I know it, but you know, I'll say "I'm depressed." But then you have to...'

Anna: 'Mm-hm.'

Kathleen: 'But you can't say to somebody "snap out of it", it just won't...'

Following discussion of their care needs the couple discussed their views on care homes and why they would not wish to go to one focusing on how they did not think that older people were stimulated in such places

Robert: 'Well, I think they don't get enough to do, do they, when they go, they just sit in a chair and stare.'

Kathleen: '[going into a home] is the last resort.'

Robert: 'Yes.'

Kathleen: 'Yeah.'

Robert: 'Not just for financial reasons but..'

Kathleen: 'I don't think they do anything when they get there, just... they just don't do anything.'

Robert: 'She used to visit my... I suppose, great-aunt till about ten years ago, every week I used to go to the... And it was a rather well-run home, I thought, but she wasn't at all happy – she wasn't a happy person, but then...! You could just see them, they were somnambulous, they just sat...'

Kathleen: 'And they'd sit and frown.'

However a move to a care home was an eventuality that remained distanced as something that they felt may be needed for ‘other’ people. More tellingly, though was the story of a friend suggesting that one would choose to die rather than live in a care home.

Robert: ‘Yes, we’ve noticed the death of one chap who had to go with his wife into a home and I think they just bankrupted themselves and one of them, the wife had Alzheimer’s pretty badly.’

Kathleen: ‘And he couldn’t stand it any longer I don’t think, stopped eating.’

Robert: ‘Turned his face to the wall and went, not that I was visiting him or close to him but I know of him well and that’s the sort of thing you dread, most people do.’

They then described their plans should their own health or function decline further. They planned to increase their care package but again this related back to care homes. *‘[The care agency] would expand their facility immediately – they say. ‘Immediately’ might be, you know, a day or two. So that’s a help. But what we would do otherwise, I don’t know. The alternative to that is a home, I suppose, as you were mentioning, but that is the last resort.’* The couple again chose to talk openly about death as something that they expected. They remained explicit in using a faith based framework for understanding their mortality.

Robert: ‘It’s not in our hand what happens’

Kathleen: ‘That’s right, it’s as the Lord wills’

Dying was an event, a before and after, no thought was mentioned of how it could happen. Instead their focus for the future was to stay together in their own home and not to burden their children.

Robert: ‘And I mean, they must have their own activities to get on with and we can’t be a burden on them, and that the LAST thing we’d want to be is a burden’ or a bother to anybody.

Robert: ‘We try our best to be not a nuisance.’

Anna: ‘Well, who are you being a nuisance to?’

Kathleen: ‘Everybody else! (laughs) Family and friends, everybody.’

Existentially Kathleen and Robert relied on their faith and on supporting each other as before.

Robert: 'What keeps me going is the fact that I'm helping'

Kathleen: 'I think our faith too keeps us going'

Bereavement Interview:

Unfortunately, 'another five years' was not to be for Kathleen, as an episode of severe chest pain resulted in an emergency admission to hospital where she died the following day. Robert was able to tell me of the circumstances surrounding the end of her life and expressed deep despair at her death which had come as a shock to him.²⁷ Kathleen's remaining months of life had been dominated by increasing pain in her feet and her hip. Their search for answers and solutions had continued and they were awaiting, with trepidation, a consultation regarding possible surgery. They understood that what was being considered was amputation of Kathleen's toes to alleviate her pain.

Robert: 'Our principal concern had become the prospect of orthopaedic intervention which was scheduled in October, the waiting list was about three months but she never got. That was what we were pinning our hopes on that we would avoid having to have her toe amputated (OK) or toes plural' 'we were afraid of having to have amputation of the toes'

Yet discussion with their GP revealed an unfortunate miscommunication. The dread they lived with was unfounded as the referral had been made to consider hip replacement surgery. *GP: 'We were waiting and waiting and waiting for the orthopaedic opinion on whether she needed a hip replacement' rather than amputation. 'I thought we might have ended up with amputation, I suggested, I hinted that that might be what we would end up with but actually we, we never needed to go down that route.'* However the misunderstanding seemed to also have

²⁷ The couple had seemed to be quite open and accepting that their lives may soon end yet the degree of shock at Kathleen's death that Robert expressed suggested that he had not been anticipating death any time soon.

extended to what the GP's understanding of what Kathleen was and was not accepting of that was in contrast to Robert's account of the events.

GP: *'But she was a realist about [the possibility of needing her toes amputated] (uh huh) so we were accepting of those things.'* The GP, however, discussed how she was not equipped to fully attend to her patients' end-of-life needs. *'GPs don't have enough time, I mean you give[people] lots of time and in a home visit package of care assessment, different assessments, different needs. And then you step back because you've done your medical management bit (mm hm) much as you know that there are social, spiritual, emotional needs ah, you haven't the time to invest in that'* She further elaborated on her difficulties coordinating between primary care and secondary care.

'A district nurse, or palliative care coordinator person, would be fantastic. Cause I think that probably we do, cause some of my experience with [Kathleen] is that we had the facilities, we had the expertise, perhaps sometime we didn't always have all the joined up story [co-ordination between specialities and teams]'

Robert, however, was simply dismayed that no one, himself included, had been able to relieve Kathleen's suffering. He believed that he had failed her.

Robert: *'Well I didn't save her did I?'*

Anna: *'Do you mean her life at the end?'*

Robert: *'Yeah. I've said it again, I'll say it once more; grief can be a selfish thing, but there's no selfishness about the efforts before (mm mhm), I was totally dedicated in my mind to helping. There are limits of course, a mere man can't do things, but she told me what to do and I did it. And we got ah these ready-made meals which helped a lot, and are still helping, which enabled us to live and live quite well in terms of creature comfort. But I could not make her better and no efforts by the doctors or anything or the nurses, they all palliated, it was all good stuff, but nothing was curable, nothing was successful in treatment (mm mhm)'*

Anna: *'Do you think that's made, did they ever say that to you or was that just what you took from what happened, that nothing is curable, or were you looking for thinking [cross talk].'*

Robert: 'I was looking perhaps stupidly, perhaps stupidly I was looking for a solution, if not a cure. We never found a solution.'

Despite the search for answers, solutions or cures it appeared that Kathleen may have anticipated her life ending but had not communicated this to Robert: *'[she'd] left a letter, Kathleen had, which I didn't know anything about, to be opened in the event of her death and em in it she said very nice things about the family which were appropriate but she said perhaps could a, a private funeral would be the most practical answer.'*

7.3.1 Concluding Kathleen's story

Although Kathleen's story had a clear beginning it was not viewed as a cause. The couple strove endlessly for restitution without knowing what Kathleen was striving to recover from. While they coped in many ways supporting each other, maintaining their faith and avoiding their fears, Kathleen's last months of life had been dominated by searching for answers to what was happening to her, and seeking relief from her pain. The medical ailments that she suffered and her ageing body did not in themselves provide adequate explanation for her physical decline. She was not able to find a new way to be herself, to adjust to her circumstances, or to carve out a new 'normal' whilst remaining in the state of uncertainty. The mutual support between husband and wife was an essential part of her existence but inadvertently may have exacerbated this situation, as he did not consider that his wife's life was nearing its end. Even if she had considered this herself she did not communicate this to him. Instead both struggled together for 'solutions', cures and for an answer as to why she was suffering as she was.

7.4 Mr Robson

‘That was it, I was stuck in the house, that was me I couldn’t get out’

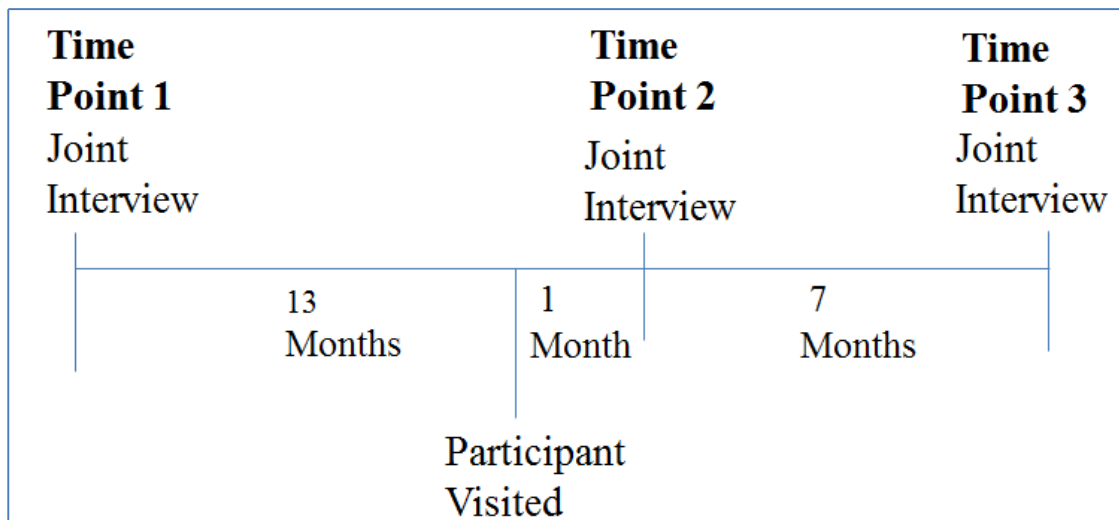


Figure 20. Time line for Mr Robson

Mr Robson was widowed and shared his council house with his son Gary having moved there with his wife from an adjacent and more deprived area some years before. I was able to interview Mr Robson and his son Gary jointly on three occasions over an extended period. I had found it difficult to contact Mr Robson following the initial interview due to his recurrent admissions to hospital and the fact that he was not able to answer his phone. I attempted to call Gary but eventually resorted to trying to find Mr Robson on hospital wards and ultimately by visiting his home. Mr Robson also had a daughter who visited most days and did the housework and washing for her brother and father in addition to looking after a disabled son and husband. I met her at the time of the third interview and her fondness of her father was clear. Mr Robson was not able to nominate a professional carer at any point.

Time point one:

Mr Robson sat in his wheelchair watching football on television with his son who had recently woken in the early evening from sleeping after night shift. The story that Mr Robson and his son gave started with a diabetic ulcer necessitating lower leg amputation which offered a clear cause for Mr Robson’s situation. The overall story

was one of restitution following the surgery and our first interview focused around the treatment of Mr Robson on discharge home from hospital. A 'battle' metaphor raged throughout the interview with both Mr Robson and Gary feeling that they had been let down by the health and social care agencies. They told of assurances given that their house would be adapted for Mr Robson before he would be sent home yet this proved not to be the case *'everything was supposed to be done before I left the hospital and nothing was done'*. They were left to organise the provision of adaptations that would enable Mr Robson to leave his home. A negotiation with the local council that was clearly difficult.

Gary: *'aye we had to fight to get them back [to put the full railing in outside]'*

Mr Robson: *'It was like drawing teeth'*

In his home, Mr Robson felt trapped as he was unable to go out of his front door *'That was it I was stuck in the house, that was me I couldn't get out'*. It was the lack of freedom to come and go that troubled Mr Robson as he was keen to remain living in his home and talked of feeling pressured to move.

Mr Robson: *'Because I don't want to move house, I like living here.'*

Gary: *'They actually wanted him to move a, but he didnae want tae'*

Mr Robson: *'I like it here'*

Mr Robson described the importance of his house in the broader context of his life. Moving there had allowed him to 'escape' from a more deprived area that he attributed to causing the stress that led to his wife's death some years before: *'that's what killed my wife eventually I think was just her nerves got the better o' her'*. This was his home now and he did not want to leave.

Mr Robson attended the day hospital where he appreciated the physiotherapy *'Ken when I wis walking I could feel [the stump] sliding back and forward, ken I wisnae happy wi' it at all so they sent me up from the [Hospital] up to the [Day hospital] and [the physio] sorted it oot up there so it's alright now'* and indeed continued to view himself as physically capable focusing on his upper body strength as evidence, *'she used tae knock hell oot o' me because I could, as I say I'd done most of the exercises when I was in the [Hospital] so it was nothing to me and the parallel bars and such like I can do all that'*. He described pride in walking into the unit using his

sticks, suggesting that he was more comfortable doing so in the public arena of that environment. Perhaps this was also to demonstrate his physical difference to those that he perceived as less able *'I've got the sticks there, I use them in the ambulance, when I'm going in the ambulance and that, around the hospital I usually take the sticks wi' me and then I can walk into the hospital'* as he cautious of walking in his home where he preferred to use his wheelchair: *'just use this chair, well I can use my sticks but I prefer to sit in my chair it saves me in case I fall or anything, you know, I feel safer in the chair for meals and that.'* He did not view himself as similar to others attending the day hospital, referring to 'they': *'I says I was the only one that was doing all the exercises all the rest of them, well most of them are all pretty old, well I'm old as well of course but they seemed to have a lot more problems than I had. I had just lost a leg but they could hardly walk a lot of them, so they were just going through the motions of the exercises really but'* implying that his reasons for requiring the day hospital were distinct from others. Where he did associate himself was in an identity as a diabetic person as his collective pronoun suggested: *'they said this is the thing with diabetics you don't feel pain, I don't know why that's how it is.'*

Mr Robson partially blamed himself for his amputation, *'as I say it was stupidity, I never noticed what was happening'* as he felt he had not dealt with his symptoms in a timely manner.

Mr Robson: *'That was my own fault I took an infection in the sole of my foot and I didn't pay much, see I'm a diabetic and I didn't pay much attention tae it and the infection was travelling up my leg so they had to whip the leg off, well I've got it, below the knee they had to take it off.'*

Gary: *'He kept his shoes on all the time and never told anybody and hoped that it would go away.'*

However Gary generalised such behaviour to a universal trait of 'older people'.

'When they get to a certain age they become stubborn and think it will just sort out itself and obviously...' though this was quietly refuted by Mr Robson later when he qualified that diabetes meant he could not recognise the severity of his symptoms *'That's what they said, they said this is the thing with diabetics you didn't feel pain, I don't know why that's how it is.'*

Generally Mr Robson described feeling abandoned by the health care system *'they discharged me too quick. They wanted the bed so I got flung out.'* His imminent discharge from the day hospital felt like a further rejection *'I enjoyed it there. I'm getting flung out next week though'.*

Social interactions for Mr Robson focused on his son and daughter and although he also attended a lunch club at a local church he did not talk of others at the programme. Other more lifelong social activities had been severed along with his lower leg, as the male orientated activities he had enjoyed such as going to the pub or to football matches were now impossible without someone else to take him.

Anna: 'Do you see friends much?'

Mr Robson: 'No I don't see many nowadays. I used to go regular to the football, I used to travel all over but I don't see anybody now.'

Mr Robson did not talk of hoping to regain any of these lost activities or about any hopes or fears for the future. Instead he focused on the events that led up to his new circumstances which he had felt that he had adjusted to and preferred now to put behind him.

'I feel alright I'm getting used to it now aye. I was a bit down when I first came out but I'm alright now, I've got used to it.'

I was able to speak to Gary in the following months although I never managed to talk Mr Robson himself. I was then unable to get an answer by telephone and further enquiries revealed that Mr Robson had been into hospital on a number of occasions. Attempts to visit him ended with arriving at a hospital ward to find that he had been discharged home. I eventually visited his home where he was welcoming and keen to talk to me, talking of family events over the preceding Christmas and his recent hospitalisations for treatment of his diabetes. We chatted for 30 minutes and he claimed that little had changed since my last visit but continued to express frustration at feeling stuck in his house. I arranged an interview some weeks hence.

Time point two:

On this occasion I, once again, spoke together with Mr Robson and his son. Many of the same irritations were described and previous stories were retold without revision. The metaphor of fighting a battle remained.

Mr Robson: 'I seemed to be fighting every time I went'

Anna: 'Uh huh. Fighting with.....?'

Mr Robson: 'Fighting the system! (laughs) Or fighting the council.'

This morality tale had now widened to negativity about the world encompassing in its broadest sense the world recession, but also closer to home to his GP practice.

Gary: '...you're supposed to get a visit for patients over 80, you're supposed to get a regular visit from your doctor but...'

Mr Robson: '...they never come near.'

Mr Robson's relationship with his son appeared to be strained as Gary openly vented his frustration at his father: *'my sister's told him, I've told him, till we're blue in the face but he doesn't listen'*. Specifically, Gary expressed irritation with his father for burning himself when trying to make a cup of tea. Gary argued that his father should have waited for him to come home, scolding Mr Robson for his impatience which he dealt with by removing his trust in his father, describing an almost infantile version of impatience: *'And if he just would have that little bit of patience for me coming in at about... I'll get in about seven o'clock in the morning so... and he's up the back of six and he just doesn't have the patience to wait. So I've locked the kettle away when I'm not here.'* Mr Robson, however re-framed the description of his impatience in a self-esteem saving manner that expressed a struggle to maintain a modicum of independence. *'I've no patience! (laughs). I'm that used to doing everything for myself, I can't get used to folk helping me, that's what it is.'* Unfortunately the relationship with family members was one of the few left to Mr Roberston as his only other social outlet remained the once weekly lunch club.

There was now a change in how Mr Robson referred to himself, involving a separation of 'self before' as different to 'self after' his amputation as he now faced his life as irrevocably changed. *'I've been used to working all my life and I've never*

bothered with anybody but I can't get used to this sitting about.' Generally he revealed a more defeatist attitude about himself in regard to his physical capacity than previously, along with a continuing sense of being trapped inside his home. Mr Robson's deteriorating eyesight also challenged his sense of normality, as it impacted on the activities of his day.

Gary: 'His sights just, er....I mean, sometimes he can't even watch TV, eh? He says he can't see the picture, just...'

Mr Robson: 'I can see the picture but it's all blurred, you know, I can sit and watch....I can see it but it's as if I was looking through a fog most of the time, you know, it's not a clear picture'

As before Mr Robson repeatedly stated that he was 'fine', 'doing OK' and still tried to draw a line under his past traumas '*...you make the best of it. Ah, but we survived,*' yet now it seemed less as an adjustment than a moral imperative, as is it was in contrast to expressions of frustration. The battle with the authorities for accommodation previously offered a focus, yet without this Mr Robson was left with the reality of his situation. When I asked about thoughts for the future Mr Robson preferred to look to the present.

Anna: 'And have you thought about how you want things to go from now on, from the future at all?'

Mr Robson: 'No...'

Anna: 'Things that would make life better or...?'

Mr Robson: 'Not really, no. I'm quite happy as I am, I'm getting along (laughs) getting... (laughs) getting rows from my son and daughter but I can live with that!'

Yet he revealed that there had been 'joking' suggestions from his daughter that he could go to a care home..

Mr Robson: 'I've never thought about [care homes], actually. My daughter keeps threatening me (laughs)...'

Anna: 'Does she! (laughs)'

Mr Robson: '...go to [name of care home]. (laughs)'

Despite the light hearted nature of the idea, Mr Robson refuted a future in a care home by appealing to the very sense of his previous self as independent. Care homes did not fit who he felt his self was.

Mr Robson: 'I don't fancy going into a home like, you know but...'

Anna: 'Mm. No most folk.....'

Mr Robson: 'I've been too independent for too long, ken.'

Anna: 'Mm hm'

Mr Robson: 'I'd take it ill out.'

Time point three:

During the preceding months Mr Robson had continued on a slow physical decline with deteriorating eyesight and increasing physical weakness. Our final interview found him fearful of walking at all and confining himself to his wheelchair *'I'm kind of getting to the stage now I'm scared to move in case I fall.....'* with the inability to leave his home fostering a sense of imprisonment.

Mr Robson: 'at times I feel as if the walls are coming in on me.'

Anna: Right. 'Would you like to get out the house more?'

Mr Robson: 'Well, I'd like to just get a breath of fresh air now and again, you know.'

Anna: 'Did you manage to sit outside at all in the summertime?'

Mr Robson: 'I can go so far but I've got to get somebody to take the chair out for me, see, and there's nobody here so I'm stuck.'

Mr Robson was beginning to view the broader world with mistrust as he now had a settled view that he had been abandoned to his own devices by society which was uncaring of older people generally: *'and as they keep saying "oh, we haven't got the money." They always plead poverty, (laughs) I don't know why they spend millions on bloody trams and they can't help the folk that need it'*. This was further evidenced by his feeling of having been neglected by his GP practice believing that the old policy of regular visits for the over 75s remained in place.

Mr Robson: 'I'm supposed to get a visit every so often from a district nurse but I never get it. Same with... because of my age I'm supposed to get a visit – I don't know if you know that – but I think every so often you're supposed to get a visit from the district nurse but...'

Anna: '...nobody comes.'

Mr Robson: '...nobody ever comes near, unless I've sent for them, you know.'

Anna: 'Mm. That's no good.'

Mr Robson: 'That was laid down, you were supposed to get a visit but I've never had it at all.'

To Mr Robson's view GPs in his practice only cared about 'drug users' and were compared negatively to the old ones now retired.

His main practical problem now centred on the profound effect that a change of insulin system had had. The previous system had a large dial that enabled him to administer his insulin. The system had been replaced by one that was too difficult for him to read due to his ever deteriorating eyesight resulting in his total reliance on Gary to give him his insulin morning and night. Gary felt increasingly constrained by this and complained bitterly of the impact on his life

Gary: 'I go to watch the local football on a Saturday but obviously I've got to be back for six o'clock, half past six at the latest so that I can get...'

Anna: '...dinner?'

Gary: 'But, for me to...'

Mr Robson: 'No, to get my injections and that.'

Gary: '...for me to plan to go away on a holiday, that's just a no-no, ken.'

Such feelings on the part of Gary were potentially problematic for Mr Robson as although he continued to visit his lunch club, his social interactions remained centred around his son and daughter. His daughter, who I met at the final interview, appeared extremely caring for her father, however his relationship with Gary appeared ever more distant and strained.²⁸

²⁸ Field Note: I am worried about how Gary spoke. He seemed angry and now talked mostly about his own life constraints rather than his dad's. Mr R looked as his feet while Gary complained. I am really glad that I met the daughter though. It put my mind at rest that Mr R is cared for. She and her father clearly adore each other and she gave him a kiss as she left.

Mr Robson now revealed a clear divide between his old self and new self: *'aye, because I've always been like that, I've always sort of had to cope. Now I'm dependent on everybody'*. His self-evaluations were increasingly negative and indicative of his frustration: *'now I'm dependent on [Gary], if he's not here I'm sunk, you know'*. His life had changed but who he was had also changed now too: *'I've never had ill health, I'm usually pretty good'*. No longer able to attribute the sole cause to his amputation, Mr Robson was becoming increasingly confused as to 'why' he was deteriorating. Although he offered a normative explanation of aging, *'it's old age creeping up on me,'* his confusion as to why his eyesight was getting worse and his questions to me as I was leaving²⁹ indicated that he did not fully ascribe to this view: *'I've been going up there for quite a while and it was going alright for a wee while but then it's... I don't know what happened; it just went down again for some reason.'*

As for the future, beyond his desire to stay in his home and avoid a care home Mr Robson simply did not claim to have any thoughts.

Anna: 'Have you looked to the future ever to see how you'd like things to go with you?'

Mr Robson: 'Not really, no. I just take days... (laughs)'

7.4.1 Concluding Mr Robson's story

Having adjusted to his life after amputation Mr Robson found restitution to his story with a new normal. However with further physical deterioration in he seemed to struggle to understand his circumstances. The amputation no longer offered explanation enough for his decreasing function and with a sense of imprisonment engendered by his physical dependence he was beginning to feel alienated from the world. He struggled to find a way to still be 'him', the independent man that he believed himself to be was becoming lost. Remaining in the home was clearly very

²⁹ Field Note: After the recorder was switched off and I was leaving Mr R looked at me and said 'I just dinnae get it, why I'm like this?' I felt bad leaving him and although he gave his usual laugh to lighten the moment I could feel his anguish.

important on an existential level to Mr Robson. This was where he felt that he had escaped to with his wife, following traumatic life circumstances, and where he could strive to hold onto a degree of personal freedom that continued to be threatened in order to maintain his safety. Unfortunately, doing so required the support of his son. I felt that this was ebbing away as Gary began to struggle with the impositions on his own life and Mr Robson with guilt at burdening his son. At no point did Mr Robson suggest that he had thought that his life may be nearing its end. Instead he lived day to day, fearing what he wished to avoid and attempting to cope with the increasing losses of his existence.

7.5 Mrs Pryor

'It's getting further and further away the future'

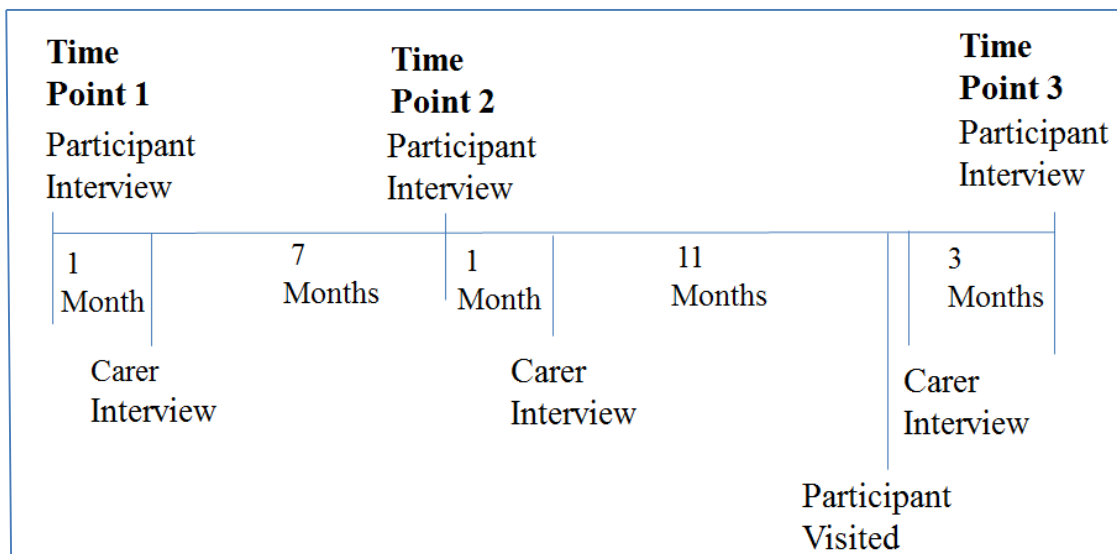


Figure 21. Time line for Mrs Pryor

Mrs Pryor lived in a detached two bedroom bungalow in a quiet cul-de-sac near a main through road of the city. She had been widowed for 20 years and had three grown sons who lived in and around the same city. However it was her daughter in law, Dorothy, who visited most regularly and who brought shopping and helped with day-to-day life. I was able to interview Mrs Pryor and Dorothy separately on three occasions. Mrs Pryor struggled to nominate an involved professional, eventually suggesting the occupational therapist at the day hospital who I was then able to interview at her place of work.

Time point one:

Mrs Pryor lived in the backroom of her home which contained a dining table and a door through to a small kitchen. She sat with her back to a large window which looked out onto a private back garden, and instead faced the door through to her hallway and to the entrance of her house as if in anticipation of an exit or arrival.

Mrs Pryor alluded to a starting point to her difficulties as following a fractured wrist after she started having falls. However, our first interview focused on single

disjointed events with a narrative form only clear in talk of daily and weekly routines. Dorothy offered the same starting point but also described what the family believed was a cause, a series of small strokes, although this had not been confirmed to them by health care staff. Mrs Pryor had agency carers who visited each day but found them unreliable and generally complained about them: *'och you never hear from them,' 'or you phone up and say am I getting somebody today, I mean I'm not fussy when they come as long as I know they're coming and oh we'll find out and we'll phone you back in a minute but that's the last you hear of them you know.'*

Her ambivalence to having carers was evident and her stance towards them which allowed her to position herself as independent and rebuff her need for care. *The trouble with me, I find that I'm mostly independent and I feel sorry for the people that really depend on [carers] that have got nobody and they're really ill you know'.* It seemed that her current situation did not reflect back to her who she thought she was: *'I never went [to the doctor] I never needed to I never needed to go,'* which was highlighted in repeated contradictory self-statements. She would state *'I was in the past a doing person rather than just sitting twiddling my fingers as I do now'* whilst following with *'I was always laid back I was a laid back kind of person at any time I think'* as she searched for a thread to tie her story and her sense of self together. Mrs Pryor also spoke of herself in a very contradictory manner suggesting that her sense of self was conflicted, and she was struggling to adjust to her circumstances as she would make a self-declaration: *'I'm basically a discontented person I think I was always out rushing around and doing things you know and now they take ill out with that, where other people are quite happy to stay in the house and never complain you know, but I'd be climbing the wall if I didn't get out at all'* and then offer the opposite *'I was getting out I was quite independent then I was walking around the house and doing things and now I'm quite happy to do nothing really.'*

The tendency to counter herself extended to defeatism about her future *'I went to turn the DVD on the other day, somebody gave me Mamma Mia which is supposed to be a very good film, I've forgotten how to work the damn thing'.* She suggested that she could knit for people but countered with *'I've got as much knitting that I've started and never sew it up'* and then *'none of [the young people nowadays] want*

anything knitted'. Even attending physiotherapy seemed fruitless to her as she did not do the exercises that they gave her 'Well they take you to physio once and then they give you exercises home which you never do of course.'

Socially Mrs Pryor did not seem comfortable with those her own age and was dismissive of their company *'I mean the worst of it is the people that I mostly mix with are all about the same age so they're not any younger, they're not getting any younger themselves you know and they're not able to do anything.'* This seemed a lifelong trait as Dorothy explained *'She wanted, you know, not to go out with her friends she wanted her children's generation more and didn't want to do this because I'm not going with all these old folk.'* It appeared to be the image that she held of old people that made her initially resistant to visiting a day centre: *'I meant I went to the day hospital someone mentioned the day centre I said me I'm not sitting with a lot of old folk sitting with their head in their chest you know'* however once she went she found she enjoyed it because of the company and the trips they took. *'They were very good we were out two or three weeks ago we were out on the Barge [at local canal] you know we went a sail on that, not very far up the river a wee bit and back, up the canal it was really in the canal and another day they took us out somewhere and I think was it [local town] or something like that we went a place I've never been for years.'*

However Mrs Pryor alluded to feeling lonely.

Anna: 'So you still manage to see people?'

Mrs Pryor: 'I still see people I see quite a lot of people.'

Anna: 'But it's getting out is the thing that doesn't....that you can't do?'

Mrs Pryor: 'No you don't get out at all. I mean at the weekend I don't like to trouble people because they're always doing their own thing you know I feel. So you could go Saturday, Sunday and never see a soul or hear from a soul at all.'

That Mrs Pryor was isolated was noted by the OT as her main problem: *'I would love to have made her less isolated (uh huh, yeah) Again it's a company thing, it's more she needed the company. If you could hire somebody to...'*

Dorothy described Mrs Pryor as having spent her life going out socially to cafés and restaurants and shopping for clothes yet these were activities now lost to her.

The importance of social interaction at an existential level was given context within the framework of Mrs Pryor's life by Dorothy.

Anna: 'And how do you think she, how do you think she copes or what keeps her going? It's quite a difficult question, but, does she have any kind of strong beliefs or any ways of looking at the world that helps her?'

Dorothy: 'She's never been a religious person, she was always....it was just she was a social person and she had her friends and that's what mattered.'

Daily interactions with carers did not offer any protection against social isolation as they were talked throughout as 'the carers' in a distanced and dismissive manner suggesting that she felt no social relationship with them. *'They're supposed to put you to bed and tuck you in but they're no good coming to me at eight o'clock at night to put me to my bed.'*

Dorothy discussed her mother in law's loneliness and her desperate calls to family. In this respect it seemed that the family were struggling to manage Mrs Pryor's social needs within their own lives *'We've all got commitments'*. Dorothy had thus considered the future where she felt that she would not be able to continue supporting her mother-in-law and had anticipated the potential need for a care home placement despite describing Mrs Pryor's resistance to the idea.

Anna: 'And it would be good for her to stay in her, it's important um you were saying for her to be in her own home as well for the future.'

Dorothy: 'Well at the minute I don't know. Nobody likes the idea of going to a nursing home but quite often they thrive on it when they go.'

When I asked Mrs Pryor about her thoughts on the future she only talked of activities that she may try to do and so moved the conversation onto another area before returning in a distanced and oblique way to her son's request that she make a will. Although this was followed by an acknowledgement that she feared the future, Mrs Pryor would not elaborate on what these fears were, using distanced personal pronouns surrounding her worries: *'I think you do get a bit frightened after a while too that you're inclined to, frightened of the day you never saw really'*. Despite having offered a starting point to her difficulties Mrs Pryor had a level of confusion

over the cause her decline: *'I don't know what's wrong with me I just get restless and I sit around doing nothing but I should do quite a lot.'* Dorothy, did not voice the same confusion but instead considered that her mother-in-law may be unrealistic about her situation, *'um but she's still convinced I think there's something they can give her that'll perk her up and she'll be able to get out and about'* and as not active in helping herself *'she wants this magic pill, she doesn't want to put the effort in'*. Mrs Pryor herself also revealed discomfort at her reliance on others using distanced personal pronouns to explain. *'You know not getting out to look around yourself at things you depend on other people.'*

Looking to the future Mrs Pryor expressed feeling of uncertainty: *'you wonder if it'll ever get better this is the worst of it you know you think this walking around can't go on forever you know.'* Yet she maintained some hope and was optimistic that her mobility could improve if she had help to go out: *'I feel if I had somebody to walk with I would walk a bit further each time you know.'* Simply being unable to go outside being a source of exasperation for her: *'what's wind and everything to you is fresh air to me you know because I never get any in here.'*

Time point two:

In the months between our first two interviews Mrs Pryor was twice admitted to hospital for extended stays following urinary tract infections. When we met again once she felt that her mobility had declined due to the physical inactivity of each hospital stay. *'You feel you get institutionalised and you move backwards instead of forwards when you're in hospital,'* and because she was unable to put much weight through her wrist thus use walking aids. Related to this Mrs Pryor had begun to admit to her increasing dependence. Still she distanced her current self frequently using the collective 'you' as a personal pronoun, *'you want to feel more independent, don't you,'* whereas the more personal 'I' was deployed in terms of negative *'there's no way I'd go [to the hairdresser] on my own, I could never walk and walk back again but, erm...'* This did not fit her understanding of who she felt herself to be *'Well, I was out all the time of course, but you miss going out.'* Having lost her place at the day centre following the protracted hospital stay, Mrs Pryor's missed the

company. *'The day that you went was quite good and you had the company too – you miss the company when you're not there'* and her relationships now focused solely on her family members. Given the previous insistence of the importance of social relationships with younger people for Mrs Pryor, Dorothy described how family relationships now held an existential value for Mrs Pryor. *'I think it was always a family orientation, especially with father, he was, he didn't have friends of his own we found really when they retired, they had their mutual friends. But it's what everybody is doing, she phones round most of the family about every day or two days and finds out, she has to know what everybody's doing and where they're going, So I think it's you know family that keeps her, her interest in that. What all the grandchildren are doing and eh.'*

Dorothy considered loneliness as her mother –in- law's main difficulty.

Dorothy: 'I think we're gonna be back to this main problem being this wanting company.'

Mrs Pryor: 'Mm mhm, that's the difficulty isn't it'

Dorothy: 'That's the main difficulty with her, she just wants people around all the time.'

However she also suggested after the interview that the family were continuing to struggle to meet Mrs Pryor's demands on them. Again the agency carers offered little in the way of social interaction and Mrs Pryor and Dorothy were openly critical of the ever- changing staff and their task orientated approach.

'She was getting different times and one day we reckon somebody came before 7am and had her all dressed before 7am and we know she had to be earlier for the day centre days then other times it would be 11am, it was different people all the time and eh they would come in and they were fussing and say "oh, they give me so many people and I'll never get round all this". Of course she felt guilty and say on it's alright I'll manage which is most unprofessional I mean, that's their problem.'

Clearly these issues created barriers to building any degree of social relationships. This was evident in how Mrs Pryor described the regular carer visits, yet continued to feel that they did not count in any social way: *'but it's a long day when you don't see anybody.'* Further Mrs Pryor complained bitterly that the evening visit to help her to bed often came as early as 7:30 or 8pm.

Mrs Pryor: 'And someone comes at bedtime.'

Anna: 'OK. And how does that work then?'

Mrs Pryor: 'Well, they just get me ready for bed and they turn the bed down and things like that but I don't bother going to bed then, I don't go till later.'

Anna: 'So what time is it they come in in the evening then?'

Mrs Pryor: 'Oh, they can come any time from eight till ten but they're most often in about half past seven.'

Anna: 'Oh dear.'

Mrs Pryor: 'I suppose some people do want to go to their bed as early as that but certainly not me.'

Despite these complaints the previous negativity and self-defeatism was absent and Mrs Pryor seemed a great deal happier and more positive about herself and her future. Her optimism continued to centre on the hope that she would regain some mobility and be able to go out of the house. *'If I get more mobile I'll be able to get out again'*. Dorothy voiced this need also: *'she's so desperate to get out.'* However continued to regard Mrs Pryor as not facing reality, which she ascribed as a general trait of older people: *'she's waiting for the next stage all the time when things are going to get better. I think she's harping back to the past when she was much more able to manage and that's very typical in a lot of elderly folk, they've not come to accept where they are at this point.'*

Mrs Pryor still voiced no other considerations of her future, yet her self-comforting statements over what she had thus far avoided suggested trepidation regarding the potential need to move to a nursing home: *'my sister yesterday was saying "oh, there'll come a day when you're not able to look after yourself, you'll need to go into a home" and I said "I damned-well won't go into a home." But the people I've heard that go into a home, they don't last very long anyway'* or of developing dementia *'I mean, I think I can cope alright at the moment. I mean, as long as you've not got Alzheimer's so your brain's still alright and you can think for yourself.'*

In the following months Mrs Pryor experienced increasingly frequent falls and was admitted to hospital where the decision was made that she should move to a nursing home. Awaiting a suitable placement Mrs Pryor went to a NHS long stay unit near her home and family, where I visited her to consider carrying out our third interview; however she requested that I delay the final interview until she had moved to the care home. Having previously arranged to see Dorothy, I carried out this interview as planned before my last visit to Mrs Pryor.

In the long stay ward Mrs Pryor was surprisingly happy and had clearly built relationships with staff members who she spoke of in social terms introducing me to those around using first names. Although the ward was large and open she enjoyed the activity that bumbled around her and could look out onto an expanse of lawn and gardens and across the city to the hills beyond through the large Victorian windows of the building. When she spoke of her impending move to a care home she voiced none of her previous resistance and was optimistic that she would have company and be kept occupied.

When I saw Dorothy she told me of Mrs Pryor's increasing falls and her need to move to a residential care facility: *'and the last week she wasn't coping at all, she kept falling.'* However I noted that Mrs Pryor's view was absent in the conversation, with the responsibility for the decision being placed with the health care team.

Anna: 'so who made the decision about where she was going to go or what was going to happen next?'

Dorothy: 'Well, the social worker makes the assessment and she asked me to go back up so she's got to see her that's what she wants to see her about today, to sign a form to say they can approach the doctor or get his opinion.'

Mrs Pryor's family seemed convinced that a move to a care home was in her best interests so had deliberated over what type of residential care would suit best. *'We want her to go into a care home rather than a nursing home because it would be more stimulating.'* They distinguished care homes from nursing homes on the basis of how stimulating they may be in consideration of Mrs Pryor's previous reluctance. *'That's one thing she says, "I don't want to end up in a place where they all just sit*

with their chins on their chests, dozing”’. Dorothy also rationalised the decision by offering Mrs Pryor’s own concerns: *‘well, it was her that said she didn’t feel happy going home....’*

I sensed a building strain in Dorothy’s relationship with Mrs Pryor as she spoke increasingly of her sense of burden.³⁰ *‘We were going down when we could but, you know, you just can’t go on like that all the time, you’ve got other commitments and all the rest of the family’*. There was also a disparity in Dorothy’s view of her mother-in-law’s circumstances and that which she believed Mrs Pryor considered for herself. Dorothy spontaneously and without prompting talked of Mrs Pryor’s life nearing its end: *‘So it’ll either be just a gradual decline or maybe then she will have a major stroke, we don’t know,’* but described more ambiguity from Mrs Pryor’s perspective: *‘But things you don’t realise she’d got into her head, she said to the doctor and to the nurse: “well, that’s not really going to happen” – we hadn’t realised that she had thought, you know, this could be a temporary thing.’*

Time point three:

When I met Mrs Pryor again she was resident in a care home in a distant and unfamiliar part of the city. I had fully expected her to be adjusting well to the move given her previous positivity and was disappointed to find her unhappy again displaying the pervasive negativity of the first interview.

She expressed bitter disappointment that the promised activities of the home had not materialised *‘Well, they said there were quite a lot of activities going on but I’ve never heard of any. But I mean, each day the other lot would be up... last night they had been at [place name] yesterday. But I think we should go out too, they said that we would go out quite a lot in this place and at the other place I was going to.’*

Although she described the staff as friendly she complained that she could not remember any names of the many and constantly changing personnel. *‘I don’t know what she was saying, She’s quite foreign. There’s so many people in here, you keep*

³⁰ This is not meant as a criticism of Dorothy who had clearly been putting in a great deal of effort to help Mrs Pryor over many years taking in weekly groceries, laundering clothing and visiting while at the same time helping with her own mother and regularly caring for grandchildren.

meeting new people and you ask their names and then you forget what they're called after a while. So many to remember' and that they frequently had accents that she could not understand *'I don't know what they say, they're all foreign in here.'* Thus, the relationships that she had built in the long stay hospital had not been replicated here once again revealing her loneliness. *'Well you find when you've somebody to talk to it's alright, it's when you're on your own all the time.'*

As for the other residents Mrs Pryor was unable to connect socially, *'they don't usually talk to you'* as she felt that most suffered from dementia.

Mrs Pryor: 'You don't understand these people, you just ignore them'.

Anna: 'and how does it make you feel when you see them being like this?'

Mrs Pryor: 'Well I think "God spare me from all this lot"'

Anna: 'mm, you must'³¹

Mrs Pryor: 'But you're gradually getting like them I think.'

This appeared to have fuelled fears of suffering from dementia herself: *'you get like them after a while I think'*. Mrs Pryor thus distanced herself from other residents entirely as was clear in the following statement where she described separation in terms that were mental and physical: *'they are all doolally through there'*. When I enquired if she attempted any social interaction within the home she was dismissive.

Anna: 'if you go [to the day room] what's everybody doing, what do you?'

Mrs Pryor: 'Just sitting either sleeping or watching television. I can't be bothered with the television, I just leave it and come through here.'

Mrs Pryor expressed herself again in powerless terms describing how coming to spend time in the residents' day room as something that was done to her: *'they put you next door,'* and a general loss of autonomy *'I'm not supposed to get up without calling them to come, which is alright when you're wanting something major but just for the little things you feel you cannot...'* which she contrasted to her life at home *'I was able to get around at home and I had carers in three times a day (mm hm?) and I was able to get around and I could cook meals and do things like that. But now I'm*

³¹ Mrs Pryor had told me when I arrived about a fight that had broken out between residents in the day room and of another lady becoming confused and distressed when talking to her.

hopeless and I've been so long not doing anything that I feel I'll never get back my stride again.'

Generally Mrs Pryor was losing interest in the outside world and activities that had previously interested her. *'You lose interest in everything really when you're in these places. (right) You do eventually say "well, I'm not interested anymore."'* She went on to describe that having previously interested in clothing, she no longer cared so I enquired about interest in other areas.

'Well, I can't think of anything right off the top of my head but I'm not so interested in people as I was before.' Mrs Pryor no longer expressed any hope for improvement and now focused on her decline

'I feel that I have gone downhill a little' and was also losing hope for the future generally. *'I feel if I pulled myself together I would be a bit better but, you know, you get into a rut, you don't bother.'*

She spoke obliquely of 'losing touch' with her future.

Anna: *'and how do you feel about the future generally?'*

Mrs Pryor: *'Oh, I don't know. It's getting further and further away, the future'*

I later asked her to elaborate on the statement.

Anna: *'so you feel the future's getting further away?'*

Mrs Pryor: *'It is, getting further away.'*

Anna: *'so you mean it feels like it's getting further away in the sense.....?'*

Mrs Pryor: *'I'm getting farther away from what's happening close at hand.'*

I considered this an expression of hopelessness and distance from her own self, her own life and a fledgling consideration of her death that to which she was not yet ready to give full voice.

She now regularly described herself in a powerless manner regularly using a distanced 'you' *'you just take it as you find it'* and no longer ascribed to a self before and after her difficulties began. There was no 'old me' that she harked back to only the 'me' of now. Any potential activities that she felt she could do were once again subject to the negative self- sabotaging of the first interview. *'I was going to crochet and attach the crochet but I didn't know how to start the damned thing.'*

Having no clear physical illness, Mrs Pryor was looking for a cause for her decline without which she could only blame the self. *'I remember once before I'd had a lot of falls and I had, er...(mm-hm...) it was medication that was causing it. But I don't know about this time, it's maybe just me. And again I suppose you would deteriorate at home and you probably do in here just the same but I don't know how that is.'*

The move to the care home was not now regarded as something that Mrs Pryor had wanted and she gave expressions of powerlessness and reflected on her lack of a meaningful choice in the matter *'I would rather be going home but I've got no choice'*. She also now described the dashing of previous hopes that any move to a nursing home could be a temporary measure. *'I said when I was compos mentis that when I got better I would go home but they said that wouldn't happen probably, if you were in a nursing home you'd be there for good.'* Once in the home it seemed like a 'sentence'

'I'm stuck with it now and I'll have to live here forever,' where the future had lost relevance.

Anna: 'How do you feel about the future with [a care home] being long term?'

Mrs Pryor: 'I don't feel very much because I don't think much about it.'

7.5.1 Concluding Mrs Pryor's Story

Mrs Pryor's story was one of striving to maintain her sense of who she was in the face of her physical decline. Although she initially struggled, over time she began to adapt, blaming frequent hospitalisations for her worsening state. However, as she again began falling and her loneliness and isolation increased, her family struggled to provide for her social needs and desires yet this support was vital for her to remain in her home. Dorothy consistently brought an ageing generalisation to bear with her mother-in-law and resisted her desire to adapt and improve as unrealistic. Thus there was a degree of disparity between Mrs Pryor and her nearest carer in their evaluations of aging. Perhaps counter-intuitively whilst in the social environment of the long stay ward she was able to feel like her old sociable self and that she belonged somewhere. She was able to build relationships with staff members and some other residents allowing her to coherently integrate her life stage into her story

of who she was. Hoping to replicate this in a care home she was bitterly disappointed at being unable to do so. This was not something that she could in any way insist on, or fight for, but was nevertheless existentially important to her. Having resisted her frail and increasingly dependent situation she began to accept and adapt initially by regarding an old and new self with physical decline attributed to hospital stays. Yet finally she relinquished her old self, unable to find a causative factor to bridge the then and now and with it any way to connect to the person she felt she was. Mrs Pryor's story had a clear beginning and I left her with a self that she was giving up on the present and the future.

7.6 Bringing the stories together

All these older people experienced gentle physical and decline over the course of the study and their social connections similarly reduced with family relationships often becoming strained. While they had a degree of community engagement and support networks, it was to a lesser extent than of the previous participants. While initially revealing hope for improvement in their lives and attaining a temporary restitution or maintaining an even keel, they became increasingly ill at ease with their circumstances as time progressed. This was highlighted by varying degrees of fear and anxiety over what the future may hold. The gradual erosion of their sense of self marked the beginnings of existential suffering as each felt a threat to a deeply valued aspect of their lives which they struggled to maintain.

All lacked a clearly understood cause for ‘why’ they were the way they were. Although George, with his progressing Parkinson’s disease, did not openly question his circumstances neither did he offer any clear explanatory account. Conversely the younger family carers in this group attributed old age as cause enough and the older people were varyingly described as not accepting this explanatory. Again, familial dynamics were crucial for the older people and they feared burdening their offspring as well as the consequences on their lives should this happen. Of the older carers, Kathleen’s husband was committed to the continued hunt for diagnoses and cures, while George’s wife, having lived with her own disability felt that her husband wasn’t adapting and accepting his own.

George and Mr Robson, with their surgical interventions, had clear medical events that had explained their difficulties and each appeared hopeful for a recovery. Both, however, seemed flattened in the subsequent months as they did not return to a level of function that they may have been hoping for, but were left trying to adjust to their declining state with no further restitution or event. George’s Parkinson’s disease was not enough to mitigate against his losses and the onslaught to his self-esteem. All the others revealed that, for them, old age did not offer an adequate reason for incapacity. Without such an explanation or ways to preserve previous identities that

could act to bridge the old and current self, the participants were left only with the self as the cause.

Looking to the end of the stories, Kathleen and Mr Mackie were unusual in their openness about dying, however closer investigation revealed that very different issues were considered. While Kathleen and her husband talked candidly about the likelihood of dying, death remained a distant event that was not imminently anticipated or planned for, while Mr Mackie awaited a sudden death that he hoped would release him from further losses to his independence. Death itself was not as feared for these older people, rather the consequences of further loss of independence as becoming intolerable burden to their family and/or admission to a nursing home, which heralded a fate considered worse than death. Even Mrs Pryor, who temporarily warmed to the idea, once it happened, began to close in on herself.

7.6.1 Narratives at the personal level: Struggling to hold on to the self

Again looking at Charmaz's loss of preferred identities, while the participants in the previous chapter managed to rebuild new identities based on adapting and retaining some aspect of their past selves, these older people seemed to initially manage this only to begin to lose it again (Charmaz, 1995). Charmaz's conditions that contribute to a loss of self (Charmaz, 1983; Charmaz, 1995) were evident in that these older people were becoming increasingly restricted in their lives and social contacts, and were beginning to lose their grasp on the factors that maintained a valued self. They also feared or sensed they were becoming a burden on society or on those around them. Each participant began to lose the ability to exercise choice and control over their daily activities, while social interactions that could potentially reduce self-worth were increasingly avoided by these older people. This limited opportunities to reconstruct a valued self. Given their fears, and occasional feelings of being a burden to their families, this would be the self that was socially reflected back to them. Further social disparity was evident between the older persons' view of their self and that of their closest relatives. Mr Robson's, Mr Mackie's and Mrs Pryor's family

members held views of generalised old age that they felt their relative fitted, yet the older person themselves was not comfortable with this thus refuted this identity. Similarly, George seemed determined that he would improve while his wife considered that his medical condition meant that he was not going to. For Kathleen, the potential conflict seemed to be that her husband willed a level of recovery, even when she herself may have realised that she was not going to recover and she could not adopt this new role or adapt to how she now was.

These older people were struggling to adapt to their circumstances because they remained at stages of still struggling against the body. By struggling *against* their failing bodies rather than *with* them there remained a hope of regaining past identities and restore the sense of self that may now be missing rather than working out attenuated versions of the self via identity trade-offs required to reconstruct the self (Charmaz, 1995). Crucial for these older people was how they experienced and defined their impairment in terms of Charmaz's stages of adapting. They lacked a clear explanation for what was happening to them thus without an obvious 'it' to adapt to they struggled *against* their circumstances. George, Mr Mackie and Mr Robson began yielding to their failing bodies or to the devalued identities attributed to it while Mrs Pryor began to give up – losing hope and crumbling inwards. Kathleen, remaining locked in the struggle for medical explanations still sought an 'it' so could not yield, resign or adapt but only struggle against nebulosity. Overall these were narratives of beginning to lose control over life and self and consequently of a place in the world.

7.6.2 Narratives at the societal level:

At a broader societal level these are stable 'core' narratives that become regressive but do not yet have the flavour of tragedy. There is a tension between societal norms of coping and self-reliance with the lived experience struggling to find a way to cope and increasing dependence. If 'coping' refers to aspects of how people maintain some sense of worth in the face of intrusive symptoms (Bury 1991 cited in: Charmaz, 1995: p273) then conveying that they were not 'coping' would affect self-esteem and

thus compromised self-worth. Increasing dependence strained the capacity to engage in meaningful reciprocal relationships with others, thus engendered burgeoning fears of being a burden on others and a social identity that was changed or lost.

All struggled with what exactly they were trying to incorporate, and were at various stages of resisting their physical decline, although without the certainty of what their resistance was against. Either a level of confusion over 'why,' or an unwillingness to incorporate an ageing or frail body as a tangible 'it' left only a level of self-blame. In terms of a broad societal narrative of the courage of the cancer sufferer that heroically fights their illness, there is a counter narrative of accepting old age gracefully that allows for no such heroic angle once the fourth age is reached. Such resistance then becomes stubbornness which itself may be viewed as a negative attribute, generalised to older people who do not do as the younger generation wish them to do. What is dignified in fighting cancer is equally undignified in resisting frailty. These stories outline the disparity in public narratives of life-threatening conditions. Where cancer invokes an imperative to battle the invading entity, frailty is equated to ageing with a dominant imperative to accept with grace. Resisting cancer is deemed dignified and strong yet strength and dignity at the end of life in frailty are found in conceding.

Professional for Mrs Pryor: I suppose it's like anybody fighting any illness, like a serious illness, some people fight and fight to the death and other folk maybe take the treatments but accept what's happening.

Chapter 8: Discussion

8.1 Introduction

The preceding chapters recounted the stories that the frail older people told according to three different narrative forms that they followed. These were

- The stable narrative, holding onto the self,
- The regressive narrative, a loosening grip on the self
- The tragic narrative, the lost self.

This next chapter begins by reframing the narratives in terms of losses across the different dimensions, physical, social, psychological and existential that contributed to threatening the sense of self and the protective factors that helped to sustain the sense of self. These are presented by following the flow of the narratives from stable through regressive to tragic.

I will follow by describing how different dimensions of need can change in relation to each other. I offer graphic illustrations of how these may change and interact over time in frail older adults in the different narratives and tentatively consider an overarching multidimensional trajectory of frailty.

I then discuss the narratives in terms of biography and consider the conditions of loss of personhood that are experienced towards the end of life that contribute to the struggle to maintain the sense of self that is central to the experience of frail older people. I then summarize the key contributions from the study before reflecting on the utility of the longitudinal, multiperspective and narrative approach taken.

8.1.1 Physical well-being - Losses

Participants all experienced a gradual deterioration in physical well-being over the time period. Most had periods where they were admitted to hospital following an acute event such as a fall or an infection. Due to their needs for physical rehabilitation and for social care, many experienced protracted in-patient stays. Following these stays, the older person was invariably weakened physically and returned home less physically capable of managing their lives than previously. Even though there was some improvement after discharge, they never quite managed a return to previous form.

The frail older people increasingly suffered from symptoms such as tiredness, weakness, pain or shortness of breath and experienced more mobility difficulties and falls. Pain was, at times, inadequately controlled due to the unacceptability of the side effects of analgesic medicines. The older people became increasingly unable to go outside or manage daily activities or roles without assistance. Ultimately, older people may die during one of the physical dips or their deterioration can take a more rapid downturn with extreme physical instability. What can then follow is a period of chaos in trying to manage their declining state before death. Initially there was a clear beginning articulated for the current frailty, usually from a period of hospital admissions or an acute physical event, which combined with a belief in the inevitable decline of ageing, allowed the older person to make sense of their situation. However as losses accumulate these explanations began to lose their salience. Lloyd et al described similar losses of the 'habitual body' in a QLLR study of those over the age of 75 in need of supportive care (Lloyd et al., 2014).

8.1.2 Physical sustaining factors

Being able to continue getting about physically was a regular refrain of the older people. Thus they valued physiotherapy and believed that it either stalled decline or helped to improve their physical strength. This could be enhanced when relatives or agency care assistants encouraged and assisted the older person to mobilise. Occupational therapy based adaptations were also helpful allowing the older people

to manage within their environment. Informal carers were able to scaffold their relatives by aiding them to undertake tasks, activities and outings that were physically beyond them. A GP that knew the circumstances of the older person well was a valuable resource for frail older people. They were uniquely able to help the older person negotiate the choices of treatment, interventions and care requirements in a patient centred holistic manner. This allowed Mrs Wood and Mrs Andrew to begin a transition to supportive and symptomatic care in a manner that was sensitive to their broader multidimensional needs. I suspect this may also have been the case for Mrs Baxter although I did not get the degree of involvement with her to be sure.

8.1.3 Social well-being - losses

Across the narratives, frail older people experienced a gradual shrinking of their social world that paralleled that of their physical condition. Many of their friends had died compounding feelings of loneliness. As they became more physically impaired they were less able to leave their homes and continue their social interactions. Some seemed to self-isolate as they increasingly rejected environments that were purely for older people, diminishing opportunities for social contact.

A sense of distance from the world that began with feelings of marginalisation from society, also noted by Nicholson et al, built over the narratives to an eventual alienation where they no longer felt that they belonged (Nicholson et al., 2012). The frail older people became ever more reliant on their family connections in the face of a diminishing social world with a building focus on one or two core relationships. A strain developed in some relationships with carers however, where carers struggled with the demands placed on them by their weakening relatives. At times the carer could no longer meet the expectations of the older person and became overwhelmed by their perceived caregiver burden (Miller & McFall, 1991). Similarly while circumstances were stable, the frail older people were very trusting in health care staff; however this built gradually to distrust and eventually a degree of conflict and loss of all confidence in these people. Ultimately, a degree of social death occurred that preceded physical death. While this may not have been to the extent of the

classical description (Sweeting & Gilhooly, 1997), it was certainly a perceived 'interpersonal irrelevancy, uninterest or even rejection by others' (Kellehear, 2007: p237).

8.1.4 Social sustaining factors

Of primary importance in supporting the social world of the older people were family members. They provided social contact themselves, assisted their relatives in maintaining other relationships as well as supporting them to negotiate the health and social care system. This is consistent with the conclusions of Tanner regarding older adults (Tanner, 2007) and Lloyd et al (Lloyd et al., 2014) describing the value of familial relationships. This extended beyond practical help in terms of providing security and protection and holding 'a central role in maintaining agency and a sense of self through the process of change and adaptation' (Lloyd et al., 2014: p15). Social well-being (closely tied here to psychological) was challenged by increasing dependence on others. There was a 'social norms based' moral imperative evident to persevere and preserve independence. In response some participants attempted to re-evaluate the help they received in more socially acceptable ways. Mr Mackie's use of a consumerist framework, Mrs Baxter's normalising help to domestic assistance and varyingly Miss Pegg's and Mr Hughes's dismissal of the necessity for outside care are examples. In a study of housebound older people rejection of help occurred because it did not fit with the self-image the older person held (McKevitt, Baldock, Hadlow, Moriarty, & Butt, 2005). Another strategy was to balance dependence by reciprocating care to others in their world, strategies described also by Lloyd (Lloyd et al., 2014) and Tanner (Tanner, 2007) who highlighted that reciprocity enabled older people to maintain balance in their relationships. Mrs Ritchie, perhaps within the normative expectations of reciprocity embedded within her faith, would listen and advise the young carers that visited and offer tokens of financial assistance as well as larger donations to her local church.

Many older people valued social interactions with a variety of age groups and some were able to build a social relationship with a regular agency carer which proved

profoundly comforting to them. This was possible for the older people when the carers took time to interact with the older person rather than taking a purely task orientated approach. Others managed relationships with younger relatives. The sense of being a burden could be alleviated by reciprocating care in what ways were left available to older people.

Other sources of protection were found when older people were embedded in their local communities. Involvement in church groups, support from neighbours, support from local services and the comfort of being a 'well kent face'³² were examples. Some valued visits to local day centres. However, not all of the participants, and none of the men, were comfortable in these surroundings due to being surrounded by 'old people' and by the focus of activities that they felt would not interest them. Those that did not value a day centre valued visits to the day hospital which was acceptable to them because it had a purpose, mainly to make them better via physiotherapy. This may have better suited the mind-set of the men and the women who had been more physically active in their youth. Tanner points to the use of community services such as bus services that can encourage feelings of belonging for older people, however such facilities were largely beyond the physical capacity of the older people in this study (Tanner, 2007).

Other measures that could enable older people to remain rooted in the world involved developing or nurturing interests. Some took an interest in nature via the wildlife in their gardens and in maintaining an active interest in current affairs via newspapers, television and radio programmes. In fact television and radio programmes were sources that were utilised by older people beyond simply offering 'company' as they enabled the maintenance of interests that could not otherwise be maintained such as following sport or dramatized social worlds.

³² Scottish colloquial term for a person that is well known in a local community

8.1.5 Psychological well-being - losses

Psychological well-being fluctuated over the course with periods where the frail older people divulged feelings of frustration, anxiety or depressed mood. These periods were related to their physical condition and a struggle to cope or adapt accordingly.

Frequently hospital admissions heralded a new degree of uncertainty; however discharge allowed some degree of optimism initially as the older person strove for a return to 'normal'. It was where this normality was not achieved that a period of adaption took place. Either the older person re-evaluated their situation to work out a new 'normal' or they began to mourn for their lost capacity and fear for the future. The older people began feeling isolated and stuck in their homes. This intensified to a sense of being trapped and imprisoned either at home or in an environment that they did not want to be in, such as hospital or a care home. Their physical limitations denied them the freedom of choice to 'walk out'.

The older participants experienced a degree of shame at their circumstances which was often manifest in the vehement rejection and distancing of the self from other frail older people. It seemed that others that were frail reflected back a reality that was intolerable to some older people. Others simply could not cope with the public display of their frailty so managed their public image in detail by avoiding situations that would display their dependence or physical vulnerability. Most of the older people complained in one way or another of the infantilising and depersonalising nature of their care and struggled to cope in response. A common complaint was the evening care service arriving in the early evening at seven or eight o'clock in the evening, akin to a young child's bed time, that would leave the older person wide awake and alone for many hours. Even the name of the service 'a tuck-in' conjured images of childhood. Finally the nature of intimate physical care that was required was frequently distressing for the older people, especially when agency staff were ever changing strangers.

Aspects of a potential future that concerned the frail older people in periods of stability merged into dread as feared outcomes loomed on the horizon. Specifically, these dreads were of nursing homes, dementia, neglectful care or becoming a burden and were considered a fate worse than death. It became apparent to me that being told that one needed to move to a nursing home was akin to a terminal diagnosis for the older people in the study. It signalled the end of the line where the self was left outside.

Many older people held on to aspects of their lives that allowed them to continue to be 'themselves' yet once this was lost became distressed psychologically. When psychological distress continued, it gave way to existential distress, despair and finally existential fatigue (Lawton, 2002) as the older person gave up.

In response to the ever reducing physical agency of the frail existence I was aware that the older people held on to the power and influence of their 'voice'. Where the body could not exercise control they could influence their worlds via voiced insistence. This, however, also deteriorated within the regressive narratives. A sense of personal agency could be shored up by the support of a carer yet fizzled to nothing when this support could no longer be maintained by which point all choice and say in life was lost.

The men in the study seemed to be at a greater disadvantage than the women in their adaptive capacity. Perhaps as women have traditionally undertaken different roles throughout their lives they were more able to adapt to this new one. The men, though, really struggled with their loss of physical capacity perhaps tied to their masculinity. Furthermore, the home may be traditionally the domain of the woman therefore confinement to this environment was something that men found emasculating. Finally, the social experiences available to older people in terms of day centres appeared to centre on more feminine activities and were resisted by the older men. Certainly the agenda of day centres seem to offer older people the capacity to interact with others their own age yet many in this study, and the men particularly, did not always wish this. They wished to interact with people based on

interests rather than age. Where this was not evident, though, was in the day hospital, which the older people regarded quite distinctly from a day centre as a place that offered, as mentioned previously, hope for improvement. What a number of the participants complained of was the need for intellectual stimulation. Perhaps, though, the day centre reflected back an image of frailty that they did not yet see in themselves and were not comfortable adopting.

Although participants described some positive experiences of their care in hospital, many experienced or witnessed neglect and maltreatment of older people. Unsurprisingly this engendered a level of fear of hospital stays especially at a stage where people may have lost the capacity for any level of voiced agency. The older people similarly described hospital stays where they may end up being kept in for an extended period. For them, this reinforced their lack of freedom and feelings of imprisonment. They could not simply self-discharge and walk out because most would have been physically unable to leave without the help of someone else. They therefore felt at the mercy of the decisions of others.

Being discharged from the day hospital service was a surprisingly negative experience for the older people. It signalled a finality of the help they could receive and their possibility for improvement, especially regarding physical therapy. Discharge felt like the health service was giving up on them. Terms that were used were *'flung out'* *'written off'* and *'given up on me'*.

Overall, expressions of hope were clearly evident while the narratives were stable but became less frequent until they were entirely absent in the tragic accounts.

8.1.6 Psychological Sustaining factors

There were a number of resilient resources and strategies utilised by the older people. During a time of stability older people offered relative comparisons with others that they considered less fortunate. These frequently evoked images of those they had seen neglected in hospitals or those that they knew that had gone to a nursing home.

These strategies also functioned to distance the reality of their own frailty by placing a worsened state away from the 'self' and onto the distanced 'other'. A similar capacity during stability was to normalise their circumstances, again described by Tanner (Tanner, 2007). There was a double edge to the commonly raised self-other comparisons however. These older people were acutely aware that they were considered 'lucky' in that they had not died at a younger age like many they knew yet, for them, this was luck of a bitter kind. There was inner conflict fed by this notion as they were left socially increasingly adrift and struggling to cope with physical decline: how could they complain?

Older people attempted to adapt to their circumstances by adapting their interests or hobbies in attenuated ways or by embarking on new ones that they could manage. Again, during periods of stability, older people were able to focus on their day to day lives and routines, a strategy that Nicholson et al (Nicholson et al., 2012) describe as allowing frail older people to root themselves in the comfort of their daily existence and has been noted in older people generally (Tanner, 2007; Agren, 1998). Daily routines also nurture a reputation to the outside world, as well as to the self, of independence as an expression of coping, and control over one's existence (Seale, 1998). Further, these daily routines may function as a proof of virtue in stoically 'getting on with it'.

Remaining within their own home was a spontaneously voiced and universal desire of the older people in this study. Nicholson et al describe similar desires that they explain as facilitating a feeling of anchorage and control that additionally strengthens the link to the past, identity and the self (Nicholson et al., 2012). That a person's home holds symbolic value as a place of familiarity, autonomy and connection to the memories of the past was described by Gott et al (Gott, Seymour, Bellamy, Clark, & Ahmedzai, 2004) however they also highlight that while dying at home may be considered ideal it can also be problematic for older people. For the participants in this study, however, their home was a place to live and was not necessarily considered in terms of a place to die. Perhaps more importantly, having a 'home' may have allowed them to feel that they were avoiding their feared fates.

A final sustaining capacity was the act of reminiscing with which the older people comforted themselves by reconnecting to their past experiences and their previously non-frail self. Reminiscence as a strategy to enhance psychological well-being has been previously articulated (Coleman, 2005), particularly for community dwelling older people (Bohlmeijer, Roemer, Cuijpers, & Smit, 2007). Talking about the past may have functioned to avoid talking about the present or the future as was clear in Miss Pegg's detailed and unstoppable family stories while she was struggling to come to terms with her physical decline. Alternatively it may have acted as a way of countering the negativity that such discussions can engender, as in the case of Mr Mackie, who seemed to enjoy the relief of talking about his younger days. Such strategies further allowed the older people to connect to their lifelong sense of self.

8.1.7 Existential well-being – losses

While maintained in the stable narratives, frail older people's sense of meaning and purpose in life eroded gradually across the regressive and the tragic narratives accompanied by increasing feelings of disconnection from the world. Existential well-being closely mirrored psychological, yet downturns occurred a little after and in consequence of psychological distress and could reach levels of despair.

The older people questioned their lives given their life stage; however they did not routinely express a fear of death. They described being aware that death was likely, given their advanced age and experiences of friends dying, yet death remained distant and abstract. It is likely that the prospect of death is not something that humans can live with for an extended period of time. One can cope in the short term, but may struggle to do so in the longer term. Perhaps we can only take so much reality.

Talk of making wills, power of attorney and getting one's affairs in order, evident in other studies of older adults (Lloyd-Williams et al., 2007; Carrese et al., 2002), was commonplace. Actual consideration of death was largely absent in the stable and regressive narratives, a clear exception being Mrs Baxter. Perhaps for this lady, her diagnoses and treatment of cancer some years before had led to a contemplation of

mortality. The older people began to fear what lay ahead for them in terms of how they may have to live as opposed to how they may die. This was less about uncertainty, but rather reflected a degree of fear and dread of the future. It was within the tragic narrative that dying became a reality. Peace with the fact, however, was only gained very close to death for Mrs Howie, in the recognition of her imminent death and final release from her existence and for Mrs Gray after one of a number of 'last rites' finally granted her the peace to allow herself to die.

Cable-Williams and Wilson found residents in long term care facilities, who were aged over 85, held general awareness of death characterised by an appreciation of human mortality and their own proximity to death given their advanced old age (Cable-Williams & Wilson, 2014). Clinical awareness of impending death, however, was only acknowledged when death was likely within a matter of hours or days. Similarly, housebound people aged over 75 were reported as planning for death in terms of its aftermath but were reluctant to engage with the future generally, preferring to live from day to day and to consider illness or dying when the time came (Carrese et al., 2002).

8.1.8 Existential sustaining factors

As mentioned before, the strategy of living day to day could also be seen as an existential one. The older people gained existential comfort in a variety of ways that were highly salient to the individual and related to the older person's sense of who they were. A frequently voiced focus on family relationships resonates with what Mackinlay (1998 cited in (MacKinlay, 2006) described in care home residents and termed 'meaning in relationship'. Similarly McKevitt et al concur with the sense of meaning and purpose in life that older housebound people attached to their family relationships (McKevitt et al., 2005). Building on this, many focused on gaining meaning and purpose in life by helping others or remaining in their home environment where they felt they belonged by virtue of family history or current relationships. Religious beliefs and practices were highly important to some who greatly valued the help and adaptations of local community church services that

enabled them to maintain their faith. However, religious faith was not an aspect that was often communicated to me by some older participants even when their carers described these. I thus need to be reflexive about the possibility that my approach may have inhibited, or at least not promoted, disclosures of this nature. Alternatively, I consider whether spiritual concerns of faith may be less prevalent while older people remain in the community, as McKinlay suggested, or that they come to the fore with the realisation of impending death as was the case for Mrs Gray (MacKinlay, 2006).

8.2 Interrelating dimensions

Within each of the sections of loss and sustaining, it is evident that different dimensions are interrelated and difficult to tease apart. Physical restrictions affect social opportunities which can lead to isolation and loneliness, while psychological distress can affect the confidence to mobilize, leave the house and willingness to interact with others. How these dimensions change over time was not clearly discernible by comparing time points for the interviews because participants were at different stages along the frailty trajectory. There were not clear time points, such as disclosure of prognosis or diagnosis or obvious proximity to the end-of-life, while as previously mentioned, there was a great deal of heterogeneity in the physical situation of the older people. However, it may be that what can be compared are the different narratives which may actually better describe the frail trajectory based on non-physical dimensions. Accordingly I tentatively propose graphic illustrations of multidimensional change, via narrative trajectories of frailty that describe change over a narrative rather than change over chronological time. These are visual representations of potential change rather than quantifiable realities and predictions for frail older people. Each X axis depicts change over the narrative while the Y axis is used to plot the continuum from well-being to distress within the different dimensions. The position on the graph of the different dimensions does not necessarily reveal any hierarchy or comparative value but rather reflects a means of illustrating how dimensional changes occur in relation to each other. The physical

trajectory is, however, outlined at the bottom because physical end-of-life trajectories tend to plot the slow lingering decline of frailty in this way.

8.2.1 A trajectory of the stable narrative - holding on to the self

Beginning with those who were managing to hold on to their sense of self the multidimensional trajectory can be plotted as follows.

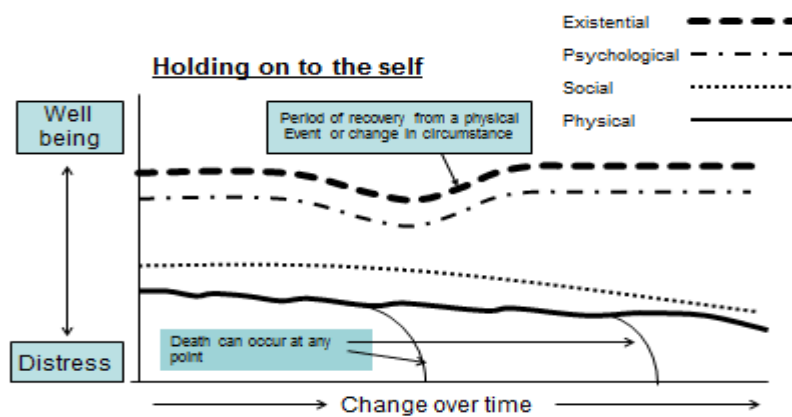


Fig 22: Trajectory of multidimensional change for the stable narrative

Figure 22 shows a gradual deterioration in the physical domain however the patterns of loss in the other areas are quite different. These older people managed to maintain their connections to the outside world and a level of social interaction and relationships with others, sometimes shifting their social focus depending on what was available. Some developed relationships with the various people who came to help them with their daily lives or with those in their local community. Some of the participants in this group initially held hope that they would improve physically. They were subsequently unhappy when this did not occur but were able to adapt to this over time and became psychologically more comfortable. Their existential trajectory largely mirrored that of the psychological.

8.2.2 A trajectory of the regressive narrative - A loosening grip on the self

For the participants who were struggling to hold on to their sense of self there was a second distinct trajectory.

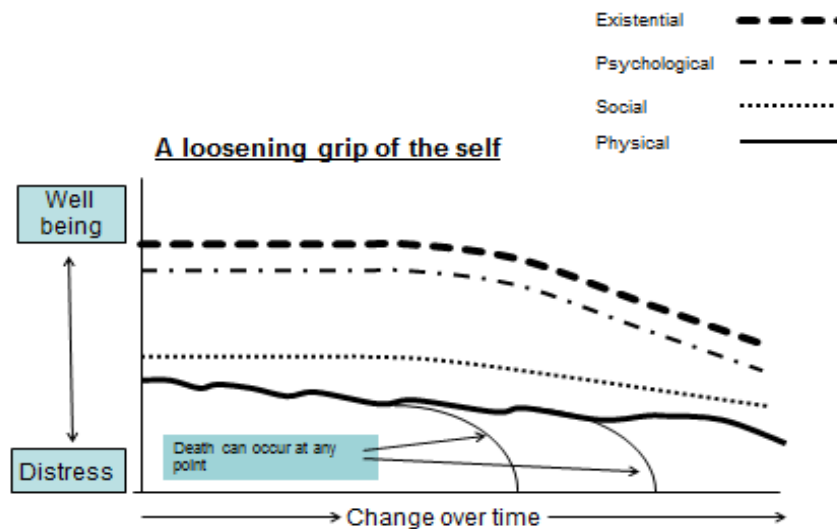


Fig 23: Trajectory of multidimensional change for the regressive narrative

Figure 23 again shows a gradual physical decline, however, this group also hoped for an improvement in their physical health. This provided a level of purpose to life as they strove for restitution. Yet when the restitution failed to happen they were not able to accept and adjust to their new circumstances and expressed frustration and unhappiness. They also characteristically revealed a level of building fear for the future, of becoming a burden to loved ones, of developing dementia or of requiring a care home. Thus their psychological and existential trajectories were sustained and then began to fall again. Social decline, however, closely mirrored physical deterioration as all struggled to maintain social connections as their physical bodies began to limit their capacity to socialise.

8.2.3 A trajectory of the tragic narrative - The lost self.

The final figure shows the trajectories of those who lost their sense of self as they reached the end of their life.

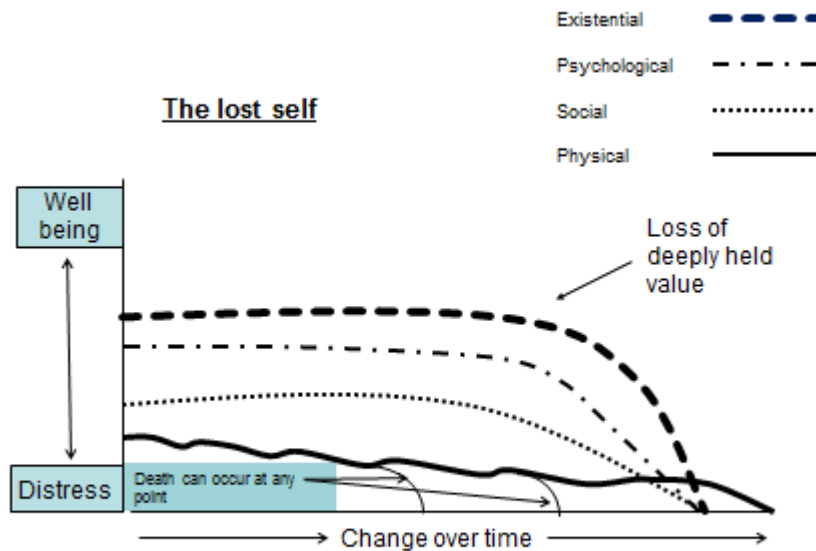


Fig 24: Trajectory of multidimensional change for the tragic narrative

The trajectory in figure 24 shows a continuing physical decline with a sharper downturn towards the end. Although a gentle physical decline was evident from the outset there was a tipping point that was reached where the older person gave up the struggle for existence. This deterioration mirrored their social decline, where each became increasingly adrift from previous relationships with others and with the outside world, leaving them ultimately reliant on a close family carer. This person was then able to shore up the older person to a point. However, once the carer reached the degree that they could no longer assist the older person to hold onto an aspect of their existence that was fundamental to who they were the older person became profoundly unhappy and distressed and subsequently lost all sense of meaning and purpose in life. It was this existential 'giving up', along with a social death and psychological despair, that closely preceded the physical death.

Although all the participants in this group died at the end of the study, there was a participant in each of the other groups that died also. What is unclear is whether those in groups the stable or regressive narratives would continue their lives in the manner suggested or move on to one of the other narrative trajectories. I suspect that some who were holding on to their sense of self may begin to struggle to do so in the face of increasing challenges, perhaps moving to one of the other two patterns. Equally, those whose grip was loosening on their sense of self may continue as they were, may manage to adjust to their circumstances and move to the more stable pattern or they may lose their sense of self entirely as they are forced to relinquish a deeply held value.

8.2.4 Bringing the trajectories together?

It seems likely that the frail older people may move in and out of periods of stability and regression and may die within these frames or may progress to the tragic narrative, given that all the participants in the tragic group died. However, since the older people in the final group all died, I considered the possibility that the distinct stories may represent a frail older person's journey during the dying process.

I have therefore brought the trajectories together to illustrate how a general end-of-life frail trajectory could look in figure 25. I must make clear, however, that these are not necessarily temporal pathways from start to finish but illustrate change across the narrative trajectories.

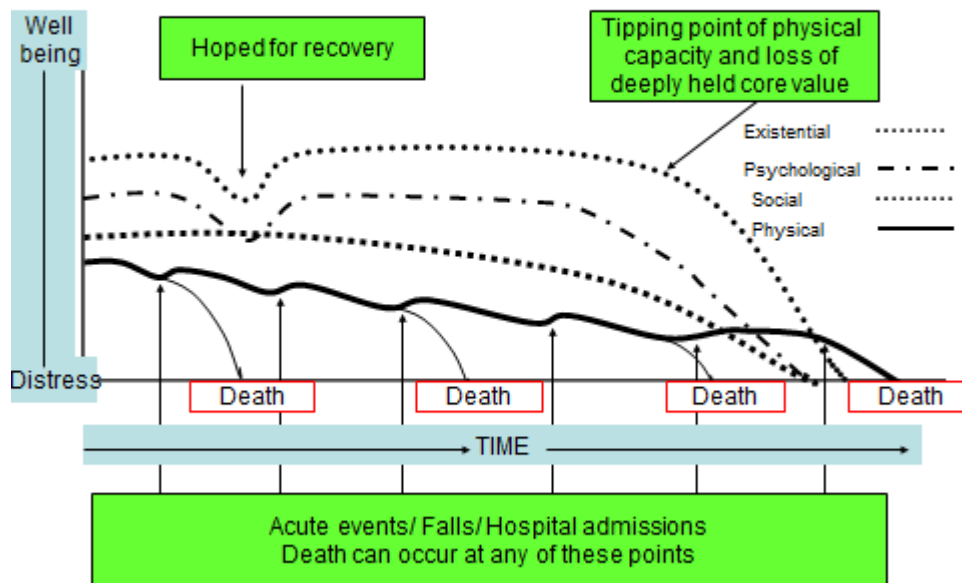


Fig 25: An end-of-life narrative trajectory for frail older people

8.2.4.1 Loss of well-being

Figure 25 illustrates a gradual, intermittent deterioration across all the domains over the course of the narratives. Social well-being closely follows that of physical well-being but without the dips that result from acute events in the physical domain. These dips may be followed by a plateau period of relative stability. Dips in physical well-being that are not fully recovered from do not necessarily result in dips in the other dimensions and death can occur at any of these points. Psychological and existential well-being also relate to physical and social dimensions although can be maintained a little longer. The psychological despair evident at the final stages of the regressive tragic narrative is followed shortly after by existential distress and fatigue.

8.2.4.2 Sustaining well-being

What was striking when teasing out loss versus sustaining factors across the different narrative types or trajectories was the fading away of sustaining capacities across all domains. Those within the stable narrative demonstrated a wide range of protective strategies however as stability decreased, resources and capacities decreased. By the

stage of the regressive and tragic narratives there were practically none evident in any of the domains.

8.3 Theoretical considerations

Moving beyond the specifics of the broad narratives I will now consider the impact of frailty on personal biography, identity and future narrative possibilities with recourse to theory. Medical sociology has attempted to understand the experience of illness at an individual and a societal level via theories of biographical disruption (Bury, 1982), narrative reconstruction (Williams, 1984) and loss of self (Charmaz, 1983). Frank proposed a typology of general narratives underlying accounts of illness which are restitution, chaos or quest (Frank, 1997). The restitution narrative involves a recovery and return to normal after the disruption of illness where individuals regain a sense of belonging in the world of the well as opposed to the world of the sick. This story is culturally embedded as the most comfortable to hear and most commonly elicited. The chaos narrative involves a lack of temporal links or coherence and implies lack of control. Chaos narratives offer no solutions or restitution and frequently involve ongoing suffering making them culturally difficult to listen to. Finally the quest narrative involves the desire to make something positive result from the negative experiences of illness. Similar to Frank, Kleinman described the value of narratives in restoring a sense of self by making sense of and coping with the effects of illness (Kleinman, 1988).

Such views on illness narratives are not without critics. Most notably Paul Atkinson whose paper 'narrative turn or blind alley' prompted a debate within the field (Atkinson, 1997). Criticism centred on the status, claims and significance of the approach to illness narratives taken by Frank (Frank, 1997) and Kleinman (Kleinman, 1988). Atkinson described Frank's work as a collection of stories with unsubstantiated assertions that lack methodological rigour. He also disputed Frank's affording of a privileged status to narrative data contesting that stories are no closer to 'authentic' feelings and experiences than other sociological data. Atkinson also criticised Frank and Kleinman for taking an overly sentimental approach that valued

therapeutic benefit over content and social context thus confusing and misrepresenting their significance. A final point of criticism was of Frank's particular focus on seeing illness narratives within postmodern notions of self and identity.

These claims were addressed by Frank (Frank, 2000) and in a similar manner by Bochner (Bochner, 2001). They refuted Atkinson's claim to objectivity in analysing narrative as misplaced. They argued that narrative interpretation is unavoidable, imbedded in personal and cultural context of the analyst, requiring thorough reflexivity. This contrasted with Atkinson's view that illness narratives should be regarded as social facts that must be interpreted without personal identification or forms of reference. Bochner further argued that the very performative nature of storytelling is an endeavour of self-understanding and meaning making. Frank responded to criticisms of the primacy of the self in storytelling as missing the point that a sense of self exists only in relation to others in our social world and that stories are inherently social. Likewise any analysis is necessarily socially framed (Frank, 2000).

8.3.1 Narrative and biography.

The experience of living with frailty involves increasing losses which disrupt, and progressively restrict, the everyday lives of older people resonating with the concept of biographical disruption in chronic illness. This involves disruption of the taken-for-granted aspects of the physical body, of daily life and relationships with the self and others where the person experiences a shift from their normal expected life trajectory that undermines self-identity (Bury, 1982).

Yet frailty is both disruptive and biographically anticipated as the older people varyingly utilised age related degeneration to explain their circumstances. The stable narratives resonate with those of older people with osteoarthritis who reportedly described their symptoms as a normal and inevitable consequence of ageing but, at the same time, as abnormal in the level of disruption to their daily lives (Sanders,

Donovan, & Dieppe, 2002). How people adapt to disruptions has been described in the theory of narrative reconstruction (Williams, 1984) in the accounts of those with a longstanding experience of rheumatoid arthritis. Williams explains that people utilise strategies that create stability and cohesion following a disruptive event “linking and interpreting different aspects of biography in order to realign present and past and self and society” (Williams, 1984: p197).

Other frail older participants, who were able to reintegrate their story and reconstruct a sense of self, voiced some level of adequate explanation for their circumstances. Those who could point to a clear starting point or cause for their difficulties could hold on to this explanation in conjunction with a belief in normative processes of ageing, allowing their situations to continue to make sense. They were thus able to live in the present and had retained a way of living that fitted their life story. In contrast, it was those who had had been the most physically fit prior to their current condition that seemed to struggle with adapting to a new self. It was in the regressive form that the narratives of frail older people offered a more ambiguous and insecure position. There is a tension at play here between normative expectations of ageing bodies and wishing for a quick end that avoids a protracted or lingering death. As Kellehear explains ‘there is a widespread fantasy that one might reach 80 or 90 years old in good health and die in one’s sleep. But the epidemiological reality is rather different’ (Kellehear, 2007: 232). What these frail older participants appeared to have expected, or wishfully anticipated, was to ‘drop dead’ rather than linger on with increasing incapacity and dependence. Further, the very expected nature of frailty is double edged as the apparent ordinariness of suffering in ageing bodies renders it invisible. It is expected, unshocking and thus unremarkable. The frail older participants offered comparisons between their own circumstances and those of other older people that functioned to distance themselves from those worse off, but also as a recognisable culturally acceptable strategy to prove oneself as uncomplaining and stoical.

Making sense of causative factors is central to the process of narrative reconstruction, yet was an area of struggle in the narrative accounts of frailty as they

become regressive. The older people expected and knew that old age brings infirmity and that frailty is ultimately likely, yet somehow did not expect it when it came. Williams's participants were long term 'sufferers' of rheumatoid arthritis whose identity was undermined by their condition and expressed identity with terms like 'this isn't me' (Williams, 1984). In contrast Sanders et al's older aged participants with osteoarthritis seemed to consider their symptoms as normal and integrated into their biographies (Sanders et al., 2002). Frail older participants in this study were content with an explanation of old age combined often with another event or illness as cause enough, so did not describe the biographical insecurities. However, when narratives became regressive, the older people became unconvinced, about the disruption to their lives, and began to question why. Old age no longer seemed enough to account for the degree of disruption that they were experiencing. This may be because it is difficult to disentangle illness from the gradually developing and nebulous quality of ageing and frailty such that any degree of demarcation may be impossible.

Sanders describes the process of diagnosis in osteoarthritis as being less clear cut than in other chronic illness thus melding with a degree of expectations of normal aging. Such distinction is even less clear in frailty which is not named let alone diagnosed. How an illness is categorised can have implications for legitimacy with frailty falling into the category of 'health problems which are not illnesses' (Cornwell 1984) with the attendant moral imperative to stoical acceptance. Expanding from this it seems that having a clear reason for incapacitates allows older people to distance the self from the situation and thus adapt better to their new circumstances. As Bury explains "the separation of disease from self is a powerful cultural resource", "To be able to hold the disease at a distance, as it were, assists the claim that one is a victim of external forces. To do anything less is to accept fully the burden of responsibility." (Bury, 1982: p172).

Williams has further argued that there may be illnesses that are biographically embedded in the individual (Williams, 2000). In a study of people who had experienced stroke Pound found that those who had previously experienced illness,

and who questioned their assumptions about their bodies and their future, did not describe the same sense of disruption to their biographies as those who had not (Pound, Gompertz, & Ebrahim, 1998). The account of Mrs Wood would be consistent with this notion. I had struggled to understand why she was at peace with her physical limitations and suffering. Yet, I began to realise that her identity was for many years incorporated as that of a person with a chronic illness when she told me that she had lived with a diagnosis of osteoarthritis. Mrs Wood had a clear causative ailment that was integrated into her life since early middle age. She did not, now, need to find a new sense of self having incorporated disability and bodily discomfort into her self-identity for many years.

It may seem surprising that the disruptions of an ageing body could be regarded with any element of blame. Yet in today's society with its rhetoric of successful aging, predicated on the ideals of youth and the imperative of retaining independence, older people are confronted with the image of failure should they not live up to such ideals. Those that have no clear reason for being frail are left with no alternative but to blame themselves. Perhaps this is an unwelcome effect of the dominant image of the active older person who reaches retirement in full physical health. This image does not fit with that of the declining frail older person. Furthermore, many of the participants had reached the age they were at, at least in part, by adopting the health seeking lifestyles of health promotion policy. None currently smoked and both women and men were eager to point out the degree of physical activity that they had undertaken throughout their lives. Others pointed to exercising the 'mind' utilising the 'use it or lose it' theory of averting dementia in later life. It is not surprising within this context that they could feel cheated of their physical robustness especially when media images portray 'super fit octogenarians'. As Gilleard and Higgs assert "frailty plays an important role in re-organizing later life along the dualism of the third and fourth age where the agency and health of the former are contrasted with the loss of those capacities in the latter." (Gilleard & Higgs, 2010: p5). Despite the cognitive acceptance that their bodies were declining due to the combined effects of old age and accumulating health issues it was not emotionally accepted in the regressive narratives without a clear reason.

8.3.2 Alternative identities

Charmaz draws on the loss of alternative valued identities as a source of suffering in chronic illness (Charmaz, 1983). In a study of people with end stage colo-rectal cancer one of the strategies that fostered the ability to reconstruct or maintain a strong sense of identity involved ascribing to a collective identity based on the illness (Carduff, 2012). Carduff argues that in doing so people thus normalized their experiences, reducing the embarrassment about illness. This was not something that the participants in this study routinely managed and in contrast many actively avoided and resisted the collective identity. Being part of a group of older people seemed acceptable, yet what separated the older people was their level of physical frailty. It was this, with the negative stereotype, that they wished to avoid being associated with at all costs.

Resisting a frail identity has been described in the literature surrounding advanced old age, with frailty described as “a residual state that remains when other narratives and other identities can no longer be asserted or enacted.” (Gilleard & Higgs, 2010: p3). Furthermore, the polarized distinction between independence and dependency, resulting from policies promoting autonomy and self-sufficiency often equated with successful active aging, result in dependency becoming “an abyss into which each of us must avoid falling” (Lloyd, 2000: p175). Lloyd further argues for the distinction between *being* and *feeling* a burden emphasising the influence of the context of how individuals are helped. This is an important distinction in understanding how older people may retain an integrated self, supported by the accounts of the frail older participants in this study. Those within the stable narratives did not express the feeling that they were being a burden on others potentially because of the nature of the social relationships in which they were helped. This finding further reveals the influence of individual circumstances on the impact of functional dependency.

8.3.3 Fearing the future

Frail older people may struggle to find a valued alternative identity, but they also must avoid a feared future identity. At an earlier stage of this study I believed that

frail older people lacked a public story for dying in the way that there exists a wealth of narratives of dying in cancer. However, through the fears that the participants raised, I realised that there was a story that was a long standing cultural belief in Western societies. “Arguably there has long been a common belief that old age is a terrible, if inevitable prospect awaiting all who do not die beforehand, where personal discomfort, material insufficiency, physical weakness and social isolation combine to place the person ‘outside’ the pleasures, activities and rewards of everyday life.” (Gilleard & Higgs, 2010: p11).

Frail older participants frequently recounted the plight of unfortunate ‘others’ that they had witnessed during hospital stays, visits to others in care homes or in stories that circulated among family and friends. These ‘others’ served almost as living symbols of what they could become (Charmaz, 1983). It is an almost shameful state of existing and fading away, accompanied by neglect, that is recognised in different ways. Seale refers to a ‘falling from culture’ through the disruption of social bonds and infantilisation (Seale, 1998). Although the older people in this study did not voice fears of physically dying, with the one possible exception who seemed to have been wrestling with a spiritual fear, it was these other states that were feared and dreaded instead. These were burdening their loved one, moving to a nursing home and developing dementia and I will consider them in turn.

Many greatly feared further loss of their independence. They dreaded not only lingering incapacity but what this would impose on their family members.

The wish not to impose on the lives of their loved ones or to be remembered in such a way is a key finding highlighted in other studies (Lloyd et al., 2014; Lloyd-Williams et al., 2007). Interestingly it appears that the very nature of frailty, given perhaps its level of normality, as expected in extreme old age is thus not considered worthy of burdening others where specific illness may legitimise such care. One participant referred to the potential for burdening his children that it would be acceptable if he had an illness. Similarly Lloyd et al describe that older people considered assistance to be acceptable in the face of specific reasons such as acute illness, fracture or surgery (Lloyd et al., 2014). This again resonates with Cornwell’s

description of difficulties related to ageing being considered as a health condition that is not an illness and thus with reduced legitimacy as a valid complaint (Cornwell, 1984).

The possibility of a move to a nursing home was spoken of in a manner akin to a terminal diagnosis. It was regarded as a dreaded event that would herald the beginning of the end at best and a fate worse than death at worst. Frail older people did not consider a nursing home as a place to go to live or somewhere that they would be cared for until they died in the manner that a hospice may be. Rather it was regarded as merely a place to exist until you no longer live that conjured images of neglect and of old people living but in a condition robbed of equal human status. What they looked to was what Kellehear described societally as ‘shameful deaths’ of the sequestered stigmatised existence (Kellehear, 2007).

Many of the frail older people voiced concerns regarding dementia. Discussion of those they had met with dementia involved pity, revulsion and rejection and many older people were keen to distance themselves from those afflicted. Older participants talked about going ‘gaga’ or having all one’s faculties and utilised terms implying that dementia would make life unbearable. Such comparisons justified a degree of security in marginalising the ‘other’ that they feared becoming. Seale, referring to Gubrium’s work with carers of those with Alzheimer’s disease, comments that people with dementia come to personify the ‘call of the dead to the living’ (Seale, 1998: p151).

These specific fears of the frail older participants seem to be scenarios that would herald a complete loss of an already eroded sense of personhood. Hockey and James anthropological work on the life course describe the increasing dependency of old age whereby ‘Very elderly people may find their freedom to choose for themselves progressively whittled away by the care they receive and consequently experience a deepening sense of lost status as persons’ (Hockey & James, 1995: p49). Ultimately becoming a burden, becoming demented or moving to a nursing home fits the conditions whereby ‘the whole person becomes known through the functioning and

competencies of the body's parts. This denies elderly people their personhood through effectively obliterating their life history and social identity and reducing them to their physical and mental disabilities' (Hockey & James, 1995: p94). Perhaps also what these feared situations signal for older people is the 'rubber stamping' of one as frail. Health has a moral element to it and despite listing many physical difficulties and complaints many people still regard themselves as healthy (Blaxter, Paterson, & Bethel, 1982). These feared states irreversibly then rob older people of the capacity to add the caveat 'but I am very healthy'.

8.4 Summarising the findings and key contributions

The issues discussed above can be summarised in the following points that present the key findings from the study.

8.4.1 Loss of self in frailty:

The frail older people experienced a loss of their sense of self as frailty progressed. However, finding ways to connect to their previous lives helped to mitigate against losses and bolster identity while social and community support was crucial in this process.

8.4.2 Lack of a cause:

The frail older people did not necessarily consider old age on its own as an adequate or legitimate explanation for decline and some were troubled as to why they were the way they were.

8.4.3 Death remained distanced:

Death was understood as on the horizon for the older people yet remained a distanced event. Talking openly of the reality of death was a rare occurrence.

8.4.4 A feared and distanced state:

The future fears of developing dementia, moving to a nursing home or burdening one's family may be the events that herald a crossing of the 'event horizon' to a reviled and rejected state of otherness where life may be deemed not worth living.

To expand on these points, the frail older people in this study experienced their declining states as an ambiguous existence that was as unfamiliar as it was unrecognised. The beginning of the story was integrated to that of the life yet explanations were sought to bring meaning and coherence to events. One is 'me' but 'not me', approaching death but not yet dying, losing independence but not dependent. One no longer fully belonged in the world but, without a positive or valued alternative identity to project the self onto, instead one is left fleeing from a devalued one.

Clear physical illness offers explanation and legitimisation of the physical and social position but also fosters a bridge between the old and new self. One can be 'me *with* cancer', 'me *with* arthritis', 'me *with* kidney failure' yet the degenerating body of old age becomes 'me' but *with* what? Those that reconstructed their narratives found alternative ways to link the old self while rationalising their frailty in terms of old age and injury or illness. There appears to be a tipping point where sustaining factors are depleted or are no longer sufficient to mitigate against the ever accumulating losses and the capacity to make these rationalisations is ever more challenged. A potential for confusion and rupture in narrative links overtakes where frail older people can then move into a desperate state of 'not yet' as they distance themselves from the end of the story. It is this despised state of otherness, existing as a non-person, which most of the frail older participants resisted being associated with and were then traumatised by when the image of the self was reflected back to them. Having presented the substantive findings of the current study I will now reflect on the methods used to produce them.

8.5 Reflections on the method

A qualitative longitudinal method proved a useful process for understanding the needs and experiences of frail older people as they change over time. A multiperspective approach proved helpful for understanding the experiences of frail older people when informal carers were included. Less overall benefit was evident when considering formal carers. I will now expand on these statements.

The potential of a QLLR (Murray et al., 2009) to understand patients' evolving experiences and needs and of multiperspective interviews (Kendall et al., 2010) to offer rich and detailed accounts of participants' experiences were reflected on in two papers which I co-authored during the course of the PhD. Thus given the focus of the current research to explore in detail the changing needs and experiences of frail older people towards the end of life I now turn my attention to reflectively evaluating the methods used.

8.5.1 Longitudinality

8.5.1.1 Capturing Change

A core aim of this study was to investigate the changing experiences of frail older people by using a QLLR approach I will first consider whether change was captured. Change being considered a key aspect of QLLR (Saldana J, 2003; Lewis, 2007) Lewis describes four types of change (Lewis, 2007). These will be considered in turn.

- The first is narrative change which refers to how stories change over time. This was clearly evident in the events that unfolded for the participants and in the changing nature of the stories especially as they changed from stable to more regressive in nature or from regressive to tragic.
- The second change is re-telling of stories by participants. The capacity for participants to reflect on or re-evaluate their experiences as the study progressed prospectively as well as retrospectively is a clear strength of QLLR (Holland J et

al., 2006). This was evident in Miss Pegg's reinterpretation of her story as she reconsidered the starting point of her difficulties over the course of the interviews. Similarly Mrs Woods reflected on and recounted her experiences through the process of deciding whether to undergo explorations and treatment for new symptoms.

- A third aspect of change is reinterpretation by the researcher.

Over the course of the interviews I saw many situations in a different light to how I had perceived them at the start. At times this involved confronting my own biases as was the case for Mrs Wood and her non complaining stoicism. What I initially took as a public story I later began to regard as an expression of how she coped. It was only through analysing in light of previous interviews and previous analyses that I was fully able to comprehend how change had occurred. While initial interviews led me to consider that participants were struggling to cope with loss, it was only through time that I could appreciate how this happened and which losses had the greater impact. Mrs Andrew had initially talked about the importance that she placed on being able to attend her bridge club. When I heard she had given up attending I had expected her to have really struggled in the aftermath, yet was perplexed that she seemed philosophical about having done so. It was at a later interview, where she explained that she now played bridge at home. I then I realised that, despite her previous claims that she now found the game taxing when trying to concentrate, her descriptions of discomfort at the club expressed that what she struggled most with was a sense of shame at the public display of some of her difficulties. I also recognised the primary importance of tennis to her but only latterly realised that following the game offered a way for her to hold on to an aspect of her life that had been of defining importance to her sense of self.

- A final type of change is where none is evident. While there were periods of little change for the participants there was usually some change in a specific area even while other aspects remained the same. However, where a situation did not change was also a relevant issue that I considered. For example Mrs Andrew

weakened and began falling, yet there was little change in her social relationships largely because of the assistance of her daughter. Similarly while Mrs Wood became gradually more physically exhausted, well-being in other dimensions remained relatively stable.

QLLR is also beneficial, however, in illustrating *how* and *why* change occurs (Holland J et al., 2006). In the early stages of the research I carried out a cursory cross sectional analysis. At the first interviews I found issues relating to loss generally. However, what could not be addressed was how and why the impact of these losses changed over time. I could not have understood how a loss in one domain could trigger losses in the others. For example, I was able to consider how the loss of a core value led to psychological distress and existential fatigue that resembled a death in those domains prior to physical death. Similarly, this process allowed a glimpse into how frail older people may be able to manage and cope with the losses that are incurred towards the end-of-life and prevent the all-encompassing distress or ‘total pain’ that was experienced by some. This positive information could help to guide interventions and improve care for frail older people.

8.5.1.2 Relationships built

A further aspect of longitudinal research worth considering involves the building of a relationship with participants. I certainly benefitted from the relationships that developed, with the older people and their carers, aided by the interim contact. This allowed the older person to understand that I was still involved in their lives and for me to understand what was happening to them. This building up of a relationship was vital in allowing the participants to talk openly about their experiences. While initial interviews frequently entailed participants telling me who they were, often including their life story, it was likely that they may have presented a more socially acceptable ‘public narrative’ (Cornwell, 1984). As I returned, the older people frequently seemed more willing to describe negatives and offer complaints rather than present a face of stoicism and coping. At times they were more verbose, but at others were more comfortable with saying less once they got to know me, and understood that I

was aware of who they were. Public accounts were often part of initial interviews. Yet participants tended to include less favourable or socially acceptable accounts at follow up interviews as they negotiated the difficult relationship between complaining and providing a public account of coping.

For some there were aspects where a private account was difficult to elicit. For example, having alluded to nursing homes to Miss Pegg, I then struggled to gain more than rhetoric from her about them. Once I had got to know her and gained her trust, however, I felt equipped to find an avenue to pursue her views via third person accounts. Over time I realised that this was a useful way to elicit views on care homes for many participants as it displaced the idea from something that may be in their future to a more generalised view. I also found myself stating that I was not suggesting that anyone needed a nursing home as I quickly realised that the topic was a ‘hot potato’ and one that participants seemed on high alert for any hints that they may be reaching that stage.

The process of relationship building was inherently valuable with the carers also. As I gained the trust of the informal carers they became more open in their approach to me and there were a number who voiced their appreciation at having someone to talk to. As one care expressed as the interview ended *‘that’s my therapy session over’*.

Relationships built were certainly reciprocal also. I was aware that the older people often seemed to desire a degree of reciprocity with me and of their underlying discomfort when they perhaps considered the relationship as one sided. There were times where a participant voiced apologies at having talked about themselves and others and where they expressed a great deal of interest in my life, my work and my family.

8.5.1.3 Constraints of longitudinal research:

There were times where maintaining contact with participants was challenging. It was not uncommon to arrive for a prior arranged interview to find no one home.

Ethically it was challenging as I had to consider if the older person was home but unable to answer the door or telephone. Having the contact details for carers was invaluable to this respect as I could quickly find out where the older person then was. Persistence was then required to contact the older person again to arrange another interview. It was not uncommon to arrive at a hospital to find that the older person had then been discharged home or admitted elsewhere.

Another difficulty resided in having an ongoing relationship with the older people and their carers. I often worried about their well-being when they were undergoing change or when times were difficult. Leaving the final interviews was also difficult as I was sorry to no longer be speaking to the older people and their carers. Some voiced their disappointment that our regular contact would stop after our final interviews while I genuinely missed the contact with many of the older people and their carers.

8.5.1.4 A multitude of selves

Reinharz described the research process as comprising of three co-existing categories of self which require reflexive attendance (Reinharz, 1997). These are the self as researcher, the brought self that one brings to the research (psychologist, nurse, mother, daughter, female) and the self that is created (active listener, confidant, friend, companion). Across the process of the PhD I have been aware of these different selves and how these have changed over time. My relationship with the participants certainly evolved over the time frame as different selves came into focus at different times and in different circumstances. Having initially considered that my academic background in psychology would be most beneficial to the PhD, I soon learned that my experience as a nurse was equally valuable, during the process of recruitment, in understanding the terminology that was used and in relating to the participants.

8.5.1.5 Iterative nature of repeating interviews

Qualitative interviews are not simply discrete events, but each interview builds on what went before, the interim communications, analysis and considerations from all parties concerned.

This was especially pertinent in the narrative nature of the interviews where I was always considering the whole story. Analysis of the previous interview guided the following interview in terms of what to expand on or explore. I was further guided on what had been missed in a previous interview or on issues that I realised had been difficult to raise or had been avoided by a participant. Furthermore, reflecting on how I had felt during interviews allowed me to see where my own discomfort may have limited discussions, enabling me to consider why this may be and to evaluate how best to approach the issue at the next interview.

There were further ways where I was called to reflect on my own emotions during an interview. For example my first interview with George and Alice was thoroughly enjoyable and I left feeling very upbeat. However the contrast to the second interview was marked as I had expected the same tone but in fact left feeling dismayed and downhearted. This difference may not have been tangible in a transcript but with the aid of my own reflections I could consider why and how the change occurred. It was often subtle changes that I noticed. For example it was the degree of change in Mrs Howie and Mrs Gray that I was startled by. Mrs Howie, by my last meeting was like a different person and I could see how she had removed herself. Her previous warmth and reciprocal interest was gone. Similarly Mrs Gray and Mr Hughes seemed to have lost a nebulous ‘something’ and I reflected on these changes through the pain of my emotional reactions. I could not have appreciated these situations as I did without having done the previous interviews. I also would have struggled to carry out one off interviews at these time points as the older people may then have been at a stage where they may have resisted engaging with someone new.

8.5.1.6 Managing a longitudinal data set

QLLR is recognised as increasing the analytical burden and this was certainly the case with this study (Holland J et al., 2006). Having attempted to use computer software to organise and manage the large data set, I could not find a method that would not result in fragmented data. Adding analysis of linked carers or professionals and different time points added to this difficulty. As the study focused on specific cases I was able to collate the interviews and analyses by sets centred on the 13 older people. This reduced the sense of a sprawling, unmanageable data set as I was always centring on the story of a specific person almost as chunks of data. A pertinent difficulty with the VCRM was the lack of literature surrounding how to analyse the data longitudinally or how to present findings. I was thus required to think creatively and create a framework for summarising the analyses in order to comprehend change over the time frame for each participant. Accordingly, a fellow researcher, Emma Carduff, and I devised visual frameworks for each analysis for comparing across time. These involved using A3 sheets of paper and plotting summary points from each of the analytical readings of each interview at each time point and with each person involved. An example may be seen in appendix 13. I could then literally draw links between time points and the different perspectives describe the nature of these links and also observe when no changes or links were notable. However, it is recognised that the analytical burden of qualitative research is effectively tripled in longitudinal work and was a component of the study that I underestimated at the outset (Holland J et al., 2006).

8.5.2 The multiperspective approach

8.5.2.1 Benefits of interviewing informal carers

Including informal carers in the process offered me a great deal of detail and context that I would have been unaware of otherwise. Mrs Ritchie's daughter was able to give me the context of her mother's anxiety, allowing me to fully appreciate the degree of insecurity and dependence on others that her mother had. Other carers offered explanations revealing issues that the older person struggled to voice. Mr Mackie's daughter was able to describe to me how her father was struggling to keep

himself going mentally when he was less likely to admit that to me. Similarly, Mrs Wood and Miss Pegg were reluctant to consider a nursing home, being at times ambivalent. However, when I spoke with their informal carers alone the picture was quite different, revealing resistance and fear regarding the possibility of going to one. Carers could offer the social dimension of the narrative allowing me to appreciate the importance of a tipping point from all the daughters in the tragic narrative group. Carers were able to describe how they managed to support the older people and how instrumental the nuances of that support were. I could understand why circumstances had unfolded in the way that they did as well as the depth of fears and the importance that certain issues held for the older people. Informal carers could also fill in the temporal gaps when the older person either forgot the details or remained focused on other aspects of their lives. However the presence of carers in the joint interviews may have stifled open discussion of some issues that the older person may not have wished to bring up in front of their family member. Kathleen and Robert are examples where this may have been the case where she may have been unable to be open about her life ending or about accepting her circumstances, given their joint quest to find solutions.

8.5.2.2 Bereavement Interviews

This additional information helped to offer an overview of circumstances that I could not have been privy to and was vital in the case of bereavement interviews which would have been very difficult had I not known the older person or the carer. The carer was aware that I knew their relative and their story and could thus talk candidly about the circumstances of the death knowing that I understood who the older person was and what their life had been like. These interviews allowed me personally to offer condolences to the bereaved relative and a level of closure for the carer but also provided a vital account of the final circumstances of the older person.

8.5.2.3 Constraints of interviewing carers

A multiperspective approach does come with elements of difficulty. Specifically, a degree of delicacy was required to ensure confidentiality when interviewing older

people separately from their carers. Thus I would not broach or express direct knowledge of what had been told to me by an older person unless the carer voiced their knowledge of it first. Also joint interviews involved an element of negotiation between the older person and the carer. Although this could be a helpful process in understanding how the relationships worked, there were times where I reflected on where one person's views were stifled by the presence of the other.

8.5.2.4 Benefits of interviewing professional carers

Where it was possible to include a professional I found a wide variation in what they could actually offer in terms of knowledge about the older person. Those that were able to discuss the older person in detail offered very valuable insights that could not have been gained otherwise. Kathleen's cause and cure seeking focus in her last months of life was clear to me yet how this had been managed by their GP was not. Further the GP interview highlighted a misunderstanding between her and her patient that unfortunately resulted in much worry and distress to the older couple. Other interviews revealed the depth of the bond held between an agency carer and an older person.

8.5.2.5 Constraints of interviewing professional carers

Adding the professional carers was of less obvious benefit than including informal carers not least in part because many of the frail older people genuinely struggled to name any person who knew them in a professional capacity well enough to be able to talk about their life circumstances. Beyond this the pragmatics of interviewing professionals was challenging. Gaining agreement to participate in the study proved difficult, with many not responding or ultimately declining to take part, as was arranging a suitable interview time in the busy schedules that these people managed.

8.5.3 Narrative approach

Having offered reflections on the longitudinal and multiperspective design I now briefly consider the analytical approach used for the study.

8.5.3.1 Narrative Interviews

In taking a narrative approach to the interviews, the questions that I asked were open and aimed to encourage the free flow of stories. These were helpful in that they allowed the participants to talk in their own time, at their own pace and at their own level of comfort and ensured that the interviews remained participant centred. I also frequently found that, even without prompting, participants would launch into telling me about their world in a storied format suggesting that they were naturally comfortable with talking in this way. There were a number of interviews where the recordings began with the participant in full flow.

8.5.3.2 Narrative analysis

The method of narrative analysis, the VCRM, came with constraints and benefits. It certainly facilitated a level of immersion in the data and promoted minimal fragmentation of the stories keeping the focus on the individual. It was through doing this that I could recognise change over time for each person within the context of the stage they were at on their frail trajectory. The different readings were particularly helpful in that they echoed the multiple dimensions considered in palliative care. Reading for the overall story brought forth issues within all the dimensions. Reading for the self highlighted physical, existential and psychological elements, reading for relationships offered an appreciation of social circumstances, while the final reading for wider world context brought to light social and existential issues. Subplots could illustrate specific events or contextual and historical detail that participants felt it was important to tell. They also suggested ways in which older people coped, for example in the tendency for some to become immersed in telling tales from their younger days.

The VCRM specific reading for the voice of ‘I’ which focuses on personal pronouns was worthwhile in that it allowed me to glimpse when the older person was perhaps distancing themselves from an issue or struggling to adapt to it. Similarly I could appreciate when they were or were not adopting a group identity by using ‘we’ or when personal pronouns were associated with verbs in a passive or active manner that could suggest expressions of personal autonomy. Finally, moments where a personal pronoun was omitted entirely were particularly telling in suggesting a total loss of say in a specific issue. For example, Mrs Howie detailed her acceptance of a nursing home with the total absence of a personal pronoun.

The analysis was most useful for offering the *form* of the stories although was less useful for eliciting specific content or themes which could have been identified using a different approach to the data. However, this very focus on *form* proved highly useful for the purpose of the study. It was evident from the initial interviews that there were not distinct stages or time points on a physical trajectory that could be discerned due to the unpredictability and protracted dying process for frail older people. It was through the use of narrative and in looking at the narrative *form* that the stories took that I was able to see familiar processes of change and types of stories. Only then could I consider comparison across time and across cases.

8.6 Concluding remarks and contribution of the thesis

In summary this thesis contributes to current knowledge in the following ways.

I have described how the changing narratives of frailty were influenced through the experiences of and mitigators against losses over the multiple dimensions. I have proposed how these dimensions may change and interrelate over the narratives and offer the potential to consider a multidimensional trajectory of frailty. This was founded on the structures of the narratives as a creative alternative to time point comparisons that are problematic within the uncertain and indistinct trajectory of physical frailty.

I have discussed how biographical disruption and reconstruction and maintaining a coherent sense of self vary across frailty at different stages and in different circumstances. What can be said about the ability to integrate a frail existence into one's story involves the wider context of the individual's life rather than simply being a natural consequence of frailty. Maintaining a sense of self, eroded in the face of loss, appeared crucial to coping and was supported by attenuating valued activities, attributing a cause beyond ageing, holding onto core values and social and community support. Holding on to these aspects enabled the older people to resist a frail identity which was exemplified in fears of becoming a burden, developing dementia or moving to a nursing home. The older people in this study did not routinely reveal an open awareness of, or engagement with, their own deaths. Few had any reason to consider this as impending, however with appropriate support could transition to a palliative approach in their medical and social care.

I have reflected on the utility of the longitudinal and multi-perspective approach and on the focus on narrative, specifically analysed through the voice centred relational method. A longitudinal approach, while with some constraints in terms of maintaining contact and overall analytical burden, was an invaluable method for understanding the changing experiences of frail older people. Similarly, the inclusion of informal carers was beneficial to the process of interviewing, for gaining greater depth of understanding in analysis and for maintaining contact with the older people. Including professional carers was helpful in some instances but of less obvious benefit overall. In the next chapter I will draw conclusions from the discussion in terms of practice, policy and future research.

Chapter 9: Implications

9.1 Introduction

Exploring frailty towards the end of life through narratives has offered insights into how frail older people experience the physical, social, psychological and existential losses that their circumstances bring and how they face these challenges. Importantly, serial interviews have offered an opportunity to consider how these dimensions change over time. The inclusion of informal carers and professionals, where possible, has highlighted where experiences are shared and how they are managed in relationship with others. This explorative study can suggest avenues that could be investigated further for health and social care services, training and policy to improve support and care for frail older people as they move towards the end of life. I will now suggest implications from the research in terms of practice and further research.

Attempts to address the unmet needs of frail older people towards the end of life may be aided by attempting to promote a cohesive narrative via integration of the self, allowing older people to hold on to core values and ways of being. These may be through attempts to reframe frailty, offering alternative acceptable identities, protecting personhood through social care practices and by addressing frail older people's greatest fears.

Palliative care as a concept or an approach may be helpful in addressing the needs of frail older people yet the models and goals remain problematic for this group. I shall consider a palliative care approach within frameworks of health and community care. Finally, I will highlight specific implications for future research surrounding the suggested end-of-life trajectories of frail older people.

9.2 Promoting the integration of the self - narrative cohesion

Given the disruption to the sense of self that increasing frailty can engender, it is worth considering ways to reintegrate the self in a cohesive narrative. Ville and Khlát consider narrative cohesion as enabling the distancing of difficult emotions related to narrated events (Ville & Khlát, 2007). They describe how building meaning and coherence is fundamental to the narrated self as an adaptive process that may facilitate coping in the face of life stresses. Yet frailty brings challenges to this capacity for a number of possible reasons that deserve further exploration.

9.2.1 Coping with the lack of a clear cause

Frail older people endeavoured to maintain a cohesive narrative, but as they strove to hold on to the sense of self they struggled with the lack of a tangible cause of their physical difficulties. Other medical conditions may challenge the sense of self towards the end of life. Where frailty differs is the lack of acknowledgement of a clear causative factor. Perhaps the assumption is that older people implicitly accept that their ageing bodies will begin to struggle. In frailty, as opposed to organ failure or cancer, there is not always an ailment to blame which, in itself, causes not only a loss of self, but may render a sense of 'self as cause'. Although chronic conditions have been linked to a degree of self-blame, i.e. smoking (Pinnock et al., 2011) or to difficult lives (Cornwell, 1984; Blaxter et al., 1982), these behaviours may be either voluntarily chosen, for example smoking, or by necessity of circumstance. These causal attributions can thus be displaced as actions or behaviours rather than onto self. Similarly, 'hard earned lives' explanations usually arise from societally based circumstances and may offer a degree of self-esteem protection from having coped through adversity as well as through the virtuous moral values of hard work and self-sacrifice.

9.2.2 Promoting valued identities

A further challenge to cohesive capacity is the lack of valued identities available to older people. They cannot map the self onto a collective identity that has any value to them in a manner that may be possible for those facing life change or uncertainty in other situations, for example in HIV (Carricaburu & Pierret, 1995). Becoming frail has cultural undertones of personal failure, possibly attributable to the modern day focus on successful ageing, which creates a dichotomy of success and failure. Rowe and Kahn define success in this arena as being free of disability and disease, functioning at a high physical and cognitive level and remaining productive and socially engaged (Rowe & Kahn, 1997). Clearly this is not realistic prospect for many older people. As Holstein and Waymack describe ‘Advertisements show us the penalty of “letting ourselves go”, and a visit to a nursing home reminds us that we too can fail (i.e., be in a wheelchair at 82 rather than sailing in the Bahamas) if we do not maintain good health habits all of our lives. If we become disabled, if we are and feel subjectively old, we are then failures with a singular goal of not entering a nursing home’ (Holstein, Waymack, Sheets, Bradley, & Hendricks, 2006: p182). ‘These ‘empirically’ based notions become implied norms’ to which older people necessarily have failed to live up to when they become frail (Holstein et al., 2006: p180). Perhaps, then, questioning the practical utility of the successful ageing agenda or at least integrating it with a realistic appreciation of and adaption to normative ageing would be more beneficial to older people than one predicated on the preservation of youth or youth orientated goals.

9.2.3 Protecting personhood through social and health care practices

Another implicit barrier to maintaining a valued self is the assault to personhood frequently cited for older people. This may be seen in the current research in health and social care practices. For example a common complaint was that older people were often visited to assist them to bed as early as seven or eight in the evening. While the ideal situation would involve a carer arriving at a later time that was more suitable to the older person, this is unlikely to be practical. Alternative approaches

could preserve the ideals of the older person. For example the purpose of this evening visit could be changed from helping the older person to bed to assisting with aspects of the nightly routine that may be difficult while leaving the rest to the older person. A good example is where Mrs Wood adapted to the early visits by readying herself for bed and then watching television in a chair in her bedroom until she was ready to go to bed. Other flexible approaches could involve helping with shoes, lower garments etc. while leaving upper garments for the older person, leaving a commode within reach and perhaps even minimal facilities for washing the face or cleaning the teeth. Creative and flexible approaches tailored to the individual would not necessitate added funding beyond initial assessment and could then reduce costs as distresses are reduced. Other threats to personhood were evident in practices reported in hospital care where the older people reported elements of being infantilised, ignored or devalued. This is a major issue, beyond the remit of the current PhD, however both social and health care practices may be encouraged over many years, through professional and public education, to foster more respectful and positive practices regarding frail older people.

Focusing on physical care, on rehabilitation and so forth, may well deny older people the support in other ways. If support could be focused on psychosocial needs, i.e. social care visits on this basis, with physical care as required, the older person would potentially be less inclined to view their frailty as a burden and as a personal failure. A feeling of being in control could be fostered for the older person if a visitor is asked to help in specific areas rather than arriving to carry out a task and then leaving. The older person could view the visits for 'them' rather than for their 'bodies'. It may be helpful to consider ways of working with social care to progress from the current task orientated focus and to build in support networks and familiarity with carers that would foster comfort and dignity when more physical care is needed. It may be worth questioning the terms used around the assistance that older people receive. For example the role undertaken by agency care workers may more appropriately be described as offering support rather than care which implicitly relates older people as a 'burden of care'. Finally a co-ordinating person between

social care, the older person and their family may be able to oversee specific individual care tailored to the individual.

9.2.4 Addressing greatest fears

A further barrier to building cohesive narratives for frail older people seems to be the nature of specific future fears that seemed, at times, to have the capacity to harness the attention of the older people thus diverting them from focusing on aspects of the present and reintegrating the self. Certainly there were avenues raised by the participants in this study that suggest very real future fears of nursing home admission, dementia or over burdening family. These could be approached and planned for to find ways of minimising fears should these events occur. The source of older people's fear of burdening is an avenue that deserves further exploration. It is addressed in Lloyd's exposition of the need for alternative models of care namely ones that foster interdependency in an ethics of care framework as opposed to focusing on independence as an idealised goal (Lloyd, 2004). The ability to reciprocate in some way could be encouraged and facilitated to mitigate against feelings of dependence. The current thesis has suggested also that feelings of independence and dependence may be more fluid and adaptable than would be implied in measures of ADL capacity. For example frail older people may be facilitated to continue performing certain tasks to circumvent or ease the sense of being dependent. Looking at fears of entering a nursing home or of developing dementia is another area of worthwhile enquiry. Perhaps there are specific aspects to these issues that could be explored. What aspects of these circumstances that older people dread could be considered. These may then be planned for, in order to reduce their capacity to induce the degree of fear, as these issues appear to hold the emotional impact akin to a 'terminal diagnosis' for frail older people. The role of nursing homes for caring for frail older people towards the end of life may be less than straightforward. If older people live in dread of such places then consideration should be taken about their appropriateness or about their current frame. Attempts to make the boundaries between the community and nursing homes more porous could help to alleviate some of the fears. For example, enabling nursing homes to become integrated into and involved with their communities may help to lessen the degree of

segregation that they may have from their settings and reduce the level of distancing and othering that those outside may feel towards those inside. This may also help to mitigate anxieties of community dwelling older adults about becoming sequestered away from their world or in some way forgotten should they need to move to a nursing home.

These suggestions reflect aspects of palliative care practice, which recommend that advance care planning in the anticipation of further deterioration in the future, be implemented for older people (Hall, 2011). Yet in a palliative care context this seems to rest on the assumption that the person is aware that their life may be nearing its end. This focus could, however, be adapted to discussions about future deterioration that do not need to consider the end of life. Detering and colleagues considered the impact of advance care planning on end-of-life in older patients (Detering, Hancock, Reade, & Silvester, 2010). Their randomised controlled trial concluded that advance care planning was helpful in identifying those nearing the end of life and was successful from the perspective of older people and their families. However, the study was undertaken during an acute hospital admission where older people may be forced to confront their imminent mortality risk. While in the community older people may not wish to consider death in lieu of living day to day. Advance care planning as it applies to cancer care may not be appropriate for frail older people. Talking about the end-of-life was not something that the older people in this study, with a few exceptions, were comfortable engaging with and most avoided the issue. Forcing older people to consider their own dying when there is no suggestion of imminence of death, or its cause, could be harmful to them in bypassing their own coping mechanisms. Instead, an aspect of advance planning that addresses the greatest fears of frail older people may foster enough reassurance to enable them to avert their gaze from feared futures, re-engage with their daily lives and find narrative cohesion.

As opposed to encouraging older people to discuss death and dying, an approach that works in a more top down manner may be to encourage openness about dying through a public health approach that encompasses dying at the end of a long life

rather than simply as a result of illness or injury McCue (McCue, 1995). Clark and Seymour found that older people describe a lack of openness about death and dying. They described predominating fears of dying alone of being left alone, lack of information about end-of-life care, belief that choices were minimal and misunderstanding or confusion surrounding end-of-life care specifically with regard to euthanasia and advanced care planning and advanced directives (Clarke & Seymour, 2010). Also described was a tendency to focus on small, personally important issues. Thus the implications of this thesis concur with Clark and Seymour's recommended focus 'on personal goals, values and everyday preferences of individuals and draw on different aspects of people's past, present, and future lives.' (Clarke & Seymour, 2010: p867).

The issue of advance planning is premised on offering choice as a way to foster control and autonomy. However, it is based on a very modern political agenda that may mean little to older generations. Older people may wish to avoid choice and the potential stress of considering alternatives. Meaningful choices are important here as some in this study had no option but to agree to something because they knew they could not manage or their family would be too burdened otherwise. What happened certainly was not what they chose. They had no option. More important than choice, however, may be agreement. In situations that do not fit with what a frail older person would have chosen, then perhaps the focus could be on finding ways to make what may seem an 'inevitable' situation more acceptable and involving the older person at every step in the decision making process as it happens. Clearly resonating here is Mrs Howie's question 'they can't make me can they?' that suggests events occurring without one's agreement. The greater stressor may be the lack of 'say' as opposed to lack of 'choice'. Choices must be meaningful to the individual, yet they are often of varying value to older people. As noted by Agich, in terms of moving to a nursing home, "Elders are typically admitted – they do not admit themselves" (Agich, 2003: p26).

9.3 Appropriate care towards the end of life

9.3.1 Palliative care?

There are difficulties inherent in trying to apply palliative care to end-of-life care of frail older people. Certainly, the focus for frail older people needs to broaden to take greater account of needs beyond the physical. What may be considered as elements of a good death in modern society involve aspects such as an 'open awareness of the imminence of death, a death at home, surrounded by friends and family and an aware death in which personal conflicts and unfinished business are resolved' (Clark, 2002: p907). These are predicated on predicting and diagnosing death and remain disease focused so are beyond the remit for most older people dying with frailty. Yet other aspects such as control of pain and other symptoms and a focus on the WHO definition of palliative care remain appropriate. What may best be described then is care towards the end of life informed by a palliative care approach. Such an approach could reduce the emphasis on the need for diagnoses, or prognosis, neither of which are necessarily appropriate or welcomed for older people. This may additionally lessen the focus on using the word 'palliative' which may well be counterproductive for older people who are likely to associate the word with dying and with cancer. Furthermore, health and social care professionals may be freed from their associated assumptions about who and what palliative care is for. The emphasis on promoting choice could be better replaced with negotiating goals of care and focusing on healing as proposed by Jerant et al (Jerant, Azari, Nesbitt, & Meyers, 2004). Such negotiations need to involve older people, their informal carers and health and social care professionals working in partnership.

9.3.2 Community health care structures

In terms of care towards the end of life for frail older people, such an august body as the WHO promotes the idea of palliative care in older people, yet the remit seems to regard older people generally, those in nursing homes or with dementia, but does not specifically address palliative care in frailty (Hall, 2011). Looking to local palliative care guidelines (NHS Scotland, 2014) there is no remit for frail older people. Within the section on frailty and dementia the internet links for information lead to

documents on dementia but none on frailty without dementia. Similarly identifying those with palliative care needs is aided by indicator tools such as the Supportive and Palliative Care Indicator Tool which includes clinical indicators together for frailty and dementia (Highe, 2013). However the very inclusion together of these issues may deter clinicians from considering the end-of-life needs of the cognitively, relatively intact frail older person. Furthermore, the inability to demarcate a point of decline that would indicate death as imminent in frailty (Covinsky et al., 2003) means that when to instigate palliative care is not clear cut and remains problematic for older people, their families and professionals (Raudonis & Daniel, 2010).

It is not surprising then that if older people do not consider themselves to be dying until very near the end of their lives and neither do health care services, then identifying frail older people for a palliative care is going to be problematic. Instead, what appears to have worked well in the current study was a person centred gradual approach. Certainly it was clear in the current research how such a gradual palliative care approach was managed by involved and trusted GPs who knew the older people well, within their personal and social context. It is these professionals who are well placed to guide services in conjunction with social care services and family members to aid older people towards the end of life. Boockvar suggested a process for family doctors approaching end-of-life needs for frail older people based first on diagnosing and classification of frailty into stages, early, middle and late, then recognition and treatment of symptoms such as fatigue depression, weight loss and weakness with palliative care input to guide professionals in management of care and advance care planning (Boockvar & Meier, 2006). The process involves establishing goals of care that can then form the basis of discussions about advanced planning, support of the older person and their family. Koller and Rockwood also recommend establishing and regularly evaluating goals of care along the course of any declining health condition and gradually introducing support and care based on optimising comfort while managing and treating acute events as they occur (Koller & Rockwood, 2013).

Support from a GP that is long standing and in the unique position of being able to appreciate the context of the older person's life can be highly beneficial for frail

older people. When this relationship works well, it has the unique capacity to gradually move from curative to symptomatic care without the requirement for diagnosis of incurability or dying which is not possible or, indeed desirable, until the very late stages of life for many frail older people. Perhaps using the Gold Standards Framework (The Gold Standards Framework, 2007) question “Would I be surprised if this patient died in the next 6 to 12 months” could be a starting point in considering frail older people’s end-of-life needs from the point of view of community based care. Potentially the familiarity with the whole person that is possible in general practice may enable the identification of a ‘tipping point’ when a palliative approach to care may be beneficial when physical problems such as pain, immobility or falls or psychological or existential distress cannot be adequately managed and begin to overwhelm a frail older person.

The Gold Standards Framework (The Gold Standards Framework, 2007) recommends that care be coordinated by a designated health care professional. This involves input from both health care professionals and older people themselves in terms of potential prognosis. It also requires the desire on the part of the older person to receive treatment, based on optimising comfort then health status based on the presence of co-morbidities, ADL dependence and declining physical performance in areas such as exhaustion and weakness. There is room for considering the utility of a named professional, such as a specialist primary care nurse, that can liaise with the older person and their family, the GP, secondary care and social care. Such a person could initiate appropriate supportive care at times of transition between secondary and primary care and further build continuity between these structures and social care services (Raudonis & Daniel, 2010; Goldstein & Morrison, 2005).

9.3.3 Health Promoting Palliative Care

A health promotion approach to palliative care could help strengthen and build community support networks that appear crucial in supporting frail older people. ‘These principles underpin the WHO public health strategy to integrate palliative care into existing health care systems and at all levels throughout the society.’

Suggested actions may be programmes aiming to ‘foster understanding of their health care needs, the acceptance of loss and dying and encouraging personal and social support at the end of life. Other aspects include recognising the social character at the core of care and loss; and reorienting health services towards community partnerships’(Hall, 2011: p19). A major goal of the WHO systems approach is to ‘improve responsiveness to non-medical expectations of the population, including two sets of dimensions, respect for people (patient dignity, confidentiality, autonomy and communication) and client orientation (prompt attention, basic amenities, social support and choice.’ (Hall, 2011: p6)

Kellehear describes the fundamental importance of building upwards beginning with the community experience and understanding of a specific issue rather than those of health professionals (Kellehear & O'Connor, 2008). This may involve endeavouring to engage with the local community or groups to ‘address their own perceived needs and develop strategies for dealing with them.’ (Kellehear & O'Connor, 2008: 113). Similarly Abel et al highlight that professional care, services and expertise, while vital, should assist rather than take over (Abel et al., 2013). Brown and Walter refer to empowering existing natural networks, be they familial or neighbourhood based and providing services where needed (Brown & Walter, 2013). Given the salience of the family, social and community networks, within which the older person is already embedded, in maximising capacity for frail older people, it is vitally important to consider interventions that may assist family carers. These may involve direct support or processes that enable carers to recognize ways in which their existing social networks could offer backing. Indeed community development programmes can offer an alternative way to structure palliative care where the person is situated at the centre of circles of care that build outwards through family, community, care services and policy (Abel et al., 2013).

9.3.4 Further consideration of tentatively suggested trajectories

A final implication is to consider the different trajectories suggested by the narratives. These were described not as a way to categorize frail older people or to predict outcomes but to offer a starting point to consider change across different dimensions. Yet they require further exploration to evaluate their resonance more broadly in frail older peoples' lives and over a longer time frame. They may also offer an alternative focus to physical change e.g. when considering moving to a palliative approach. A qualitative longitudinal approach was very useful for understanding change, yet given the long trajectory, could be even longer. I would suggest possibly understanding the frail trajectory from a baseline of social, psychological and existential issues rather than from the physical trajectory. It is within these areas that we may be able to understand changes towards the end of life more keenly than the physical, yet future research needs to follow individuals over a longer period.

9.4 Concluding the thesis

There is the potential to adapt how we approach frail older people towards the end of life at the broad cultural, social and individual levels so that more may die while maintaining a stable narrative without the trauma of the tragic narrative. In many respects this relies partly on improving attitudes to older people generally. We owe it to vulnerable old people, our future selves and those of the generations that follow to strive for improvement.

Frail older people are a piece in the jigsaw of modern deaths. They may be missed in our attentions as they may not have dementia, reside in care homes or be dying of a specified illness. These are, as Robert Burns described, the 'bending aged trees' reaching the natural end of a long life and should be able to die without becoming strangers, unknowing, unknown, unheard and unpitied.

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Appendix 1: Co-Authored Journal Article one

During the PhD I co-authored two articles with my colleagues at the Primary Palliative Care Research Group at the University of Edinburgh. This is the first.

Murray, S.A., Kendall, M., Carduff, E., Worth, A., Harris, F., Lloyd, A., Cavers, D., Grant, L., & Sheikh, A. 2009, "Use of serial qualitative interviews to understand patients" evolving experiences and needs", British Medical Journal, vol. 339, 958-960

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RESEARCH METHODS & REPORTING

Use of serial qualitative interviews to understand patients' evolving experiences and needs

Scott A Murray, Marilyn Kendall, Emma Carduff, Allison Worth, Fiona M Harris, Anna Lloyd, Debbie Cavers, Liz Grant, Aziz Sheikh

Interviewing patients over the course of their illness can give a much better picture of their experience than single interviews, but the approach is rarely used. **Scott Murray and colleagues** explain how to get the most from it

Primary Palliative Care Research Group, Centre for Population Health Sciences, General Practice Section, University of Edinburgh, Edinburgh EH8 9DX

Correspondence to: S A Murray
scott.murray@ed.ac.uk
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Longitudinal qualitative research offers considerable advantages over the more typical single "snapshot" techniques in understanding patients' changing experience of illness. Serial qualitative interviews are a convenient and efficient approach to developing an ongoing relationship between the participant and researcher, thereby facilitating discussion of sensitive and personal issues while also allowing exploration of changing needs and experiences.

Serial interview studies are widely used by social science researchers in anthropology, criminology, education, psychology, and social policy.^{1,6} However, they remain underused in medicine.⁷ Using our experience with the technique, we suggest when researchers might wish to use serial interviews and discuss the methods, the data generated, and how to avoid potential pitfalls.

When to use serial interviews

Serial interviews are suitable for research that aims to explore evolving and complex processes or when time is needed to develop a relationship between researcher and participants. We have used the approach to study the changing experiences and needs of people with lung and brain cancers, heart failure, severe chronic obstructive pulmonary disease, and spiritual distress, and access to care for south Asian patients at end of life (table, see bmj.com).⁸⁻¹¹ Others have shown the value of this approach in, for example, understanding childhood asthma, exploring stigma related to HIV infection, reconstruction of self identity after diagnosis of chronic fatigue syndrome, complex clinician-patient interactions around requests for physician assisted suicide, and the symptom course in childhood cancer.¹²⁻¹⁶

Serial interviews can also be used to identify changes in what patients want, the most acceptable way to carry

out interventions, and which outcomes are most important to patients at what times. Allowing the participant-researcher relationship to develop over time enables the generation of more private accounts and descriptions of sensitive topics that are less accessible in initial interviews. Serial interview studies can also be embedded within complex intervention studies in order to try to elucidate causal pathways. For example, we are including serial interviews in our trial of using lay outreach workers for smoking cessation in order to understand why they are (or are not) effective.

How do you conduct serial interview studies?

Recruitment

The timing of initial recruitment is important and is best driven by a sound understanding of the likely trajectory of the illness and the main issues to be explored.¹⁷ For example, we recruited patients with lung cancer at the point of diagnosis; those with heart failure at the time of their admission to hospital—when supportive and palliative care needs become particularly relevant; and patients with glioma before formal diagnosis in order to capture their experiences from this distressing time onwards. However, when prognostic uncertainty is great, the timing of recruitment for initial and subsequent interviews can be difficult to determine.

Location of recruitment also needs consideration. Identification in hospital can be successful for patients with rare conditions, who can then be followed up in the community. However, different situations may require recruitment in other healthcare settings or even outside health care. Irrespective of where participants are recruited from, working closely with all professionals involved is crucial to ensure appropriate and ongoing access to participants. In order to make the best use of resources inclusion and exclusion criteria must be well defined, including the stage of the illness.

Data generation

Variable attrition rates and illness progression will affect the timing of second and subsequent interviews. For example, we used three month intervals in people with recently diagnosed lung cancer but six monthly inter-

SUMMARY POINTS

Serial interviewing studies can give important insights into patients' changing experiences of illness

The increased contact with participants allows a deeper relationship to develop, facilitating discussion of sensitive issues

Theoretical and methodological concerns can be overcome with careful planning

Although the method is time consuming, the benefits are well worth achieving

views in people with chronic obstructive pulmonary disease, which progresses less rapidly. Researchers should identify expected transitions or key points in the course of an illness and return to speak with participants at those stages. We have also found it useful to use telephone contact to assess if an interview should be brought forward to capture a changing event. The time needed for repeat interviews must be factored into the research design timetable.

Data generation must continue long enough to describe and understand the trajectory being studied. In patients with lung cancer, for example, data collection for 12 months from diagnosis will capture most deaths, but longer will be needed in a study of frail elderly patients.

Analysis

Initial analysis of transcripts of individual interviews and field notes should take place immediately, alongside continuing data generation. This allows emerging themes and concepts to be further tested and developed in subsequent interviews. Analysis may also be done across all first, second, and subsequent interviews or data synthesised from interviews at specific key points, such as immediately preceding death.

Adequate time and resources need to be allocated to allow the various longitudinal analytical opportunities to be fully exploited. Analysing all transcripts for each person as a longitudinal single unit will provide a sense of individual experience, whereas broad thematic approaches build cross-cutting themes, but at the expense of individual contexts. The longitudinal datasets generated, being typically rich in narratives, allow innovative approaches to both transcribing and analysis. For instance, as the required coding in qualitative analysis can result in fragmentation and de-contextualisation, we have transcribed some parts of the interviews of heart failure and lung cancer patients in stanza forms, as epic poetry. These can provide an accessible insight into the patient's experience.

What type of findings might you expect?

Issues that change over time

Serial interviews can elicit changing needs or opinions—for example, in our lung cancer study some participants went from initial enthusiasm about having chemotherapy to regret, and others from refusal to deep appreciation of hospice care in later interviews. We were also able to capture the fluctuating existential anguish of increasing physical and cognitive debility in serial interviews with glioma patients and their carers. Similarly, Baker and colleagues interviewed bone marrow transplant recipients and noted changing physical problems and anxiety levels as the treatment progressed, with a feeling of impending doom emerging in later interviews.¹⁸ The serial interviews provided a rich insight into the multifaceted roles of patients within their families and communities and the way in which these served to preserve patients' identity over time.

Serial interviews can also show how patients' experiences can be affected by external factors such as the

influence of health services on their conceptualisation of illness over time.^{19,20} Furthermore, serial interviews allow fluctuating and often asynchronous patterns of physical, social, psychological, and spiritual distress to be discerned. The approach allowed us to map typical trajectories of physical decline in people with cancer and organ failure.²¹ We were also able to identify typical but asynchronous trajectories of psychological, social, and spiritual distress as disease progressed in patients with advanced lung cancer.^{21,22} We were able to describe archetypal typologies of decline by following individual cases over time. This gave a much clearer picture than would have been possible by simply comparing snapshot data at different stages in the disease.

Rich and contextualised accounts

Repeating interviews allows narratives to unfold, revealing the complexity of individual situations, and helps participants and researchers to highlight deficiencies of care and make suggestions to improve services. Experiences since the last interview can be shared, with the earlier findings being developed and reflected on in the context of an evolving, participant-researcher relationship. The resulting continuous and changing account would be difficult, if not impossible, to construct from a series of snapshot interviews. Additionally, the trust fostered by repeated contact enables participants to voice sensitive or embarrassing issues and allows more private (as opposed to public) accounts to emerge.²³ We have found that repeated interviews give participants implicit permission to broach what was previously unspeakable, facilitating frank and honest discussions that might otherwise not have occurred. Detailed and contextualised accounts of sensitive illness experiences can therefore emerge.

Pitfalls and how to avoid them

Ethical issues

Ethical problems are potentially heightened in longitudinal research, including concerns around serial consent, especially if the patient is deteriorating or vulnerable.^{19,24} Intrusion, dependency, and distortion of life experience must also be avoided.²⁵ But we have found that patients can, and indeed want to, talk about personal and sensitive issues such as death, dying, and bereavement. Patients have said that it is sometimes easier for them to talk to a researcher rather than a clinician about these issues, and that by voicing their internal fears they have been more able afterwards to speak to their family members and friends. Serial interviews also give participants the opportunity to voice their concerns and distress and make a societal contribution through research in response to the care they have received.^{26,27}

Serial interview research can place considerable demands on researchers because it is inherently an emotionally charged process. Researchers' responsibility does not end with a final interview, and it is important to protect the wellbeing of researchers as well as participants. Accordingly, we recommend counselling and debriefing sessions for both researchers and transcribers, who should ideally have adequate maturity, experience, and access to personal or emotional support.²⁸ Our experi-

ences confirm that these concerns about wellbeing can be adequately addressed and that interviewing very ill patients need not be exceptionally stressful.²⁸

Attrition

As with any longitudinal research, attrition can be problematic. For example, in one study of people with glioma, none of the planned second interviews were possible because of participants' cognitive decline and lack of energy after radiotherapy.²⁹ Steinhauser and colleagues emphasise the importance of establishing participant-interviewer rapport from the first point of contact to try maximise retention.³⁰ If a firm relationship is built up between researcher and participant, few participants will be lost, except through debility or death. Nonetheless, attrition should be factored into the design of the study. We found that by recruiting and interviewing patients and their relatives early in their illness we were able to establish relationships that facilitated interviews with relatives after patients' deaths. Grieving relatives often felt more able to take part in a bereavement interview with someone they knew and trusted, and who knew and understood their journey.

Data overload

The serial interview approach inevitably generates a large volume of interviews. The data can become difficult to manage, particularly when second and subsequent interviews have started. Effective planning is therefore essential from the outset. Furthermore, the time consuming nature of the analysis creates the danger that the process is becoming unmanageable—something that has been described as an analytical albatross.³¹

Conclusions

An understanding of the dynamic effects of disease on people's everyday lives is a prerequisite to delivering more accessible and acceptable care. People centred longitudinal research methods can make a major contribution to our understanding.³² Serial in-depth interviews are a powerful method that resonates with the clinical aim to provide continuity of contact with patients and their families. The method is also possibly the most affordable in-depth data generation technique, and our experiences suggest that it is also likely to prove acceptable to clinicians.

Lack of awareness and concerns about some theoretical, methodological, and planning considerations currently limit use of this study design. Many of these barriers can be overcome with appropriate planning and groundwork, and although the approach is research intensive, we believe the benefits are well worth achieving. Participants consistently report serial interviews as helpful rather than harmful; researchers also find that such interviewing can be rewarding.²⁴

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Contributors: SAM, MK, and AS conceived the paper, and all the authors wrote it and have approved the final draft. SAM is the guarantor.

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Provenance and peer review: Not commissioned; externally peer reviewed.

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Appendix 2: Co-Authored Journal Article two

This is the second article that I co-authored with my colleagues at the Primary Palliative Care Research Group at the University of Edinburgh.

Kendall, M., Murray, S.A., Carduff, E., Worth, A., Harris, F., Lloyd, A., Cavers, D., Grant, L., Boyd, K., & Sheikh, A. 2009, "Use of multiperspective qualitative interviews to understand patient's and carer's beliefs, experiences and needs", *British Medical Journal*, Vol. 340, 196-199.

<http://www.bmj.com/cgi/content/full/bmj.b4122>

RESEARCH METHODS & REPORTING

Use of multiperspective qualitative interviews to understand patients' and carers' beliefs, experiences, and needs

Marilyn Kendall, Scott A Murray, Emma Carduff, Allison Worth, Fiona Harris, Anna Lloyd, Debbie Cavers, Liz Grant, Kirsty Boyd, Aziz Sheikh

A better understanding of the needs of patients and their carers can help improve services. **Marilyn Kendall and colleagues** describe how to conduct multiperspective studies

Centre for Population Health Sciences: General Practice Section, University of Edinburgh, Edinburgh EH8 9DX

Correspondence to: M Kendall
Marilyn.Kendall@ed.ac.uk
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Linked interviews conducted with patients and their informal and professional carers can generate a richer understanding of needs and experiences than the single perspective most commonly used in qualitative studies. Interview dyads or triads, where two or three participants are interviewed as a set or case study, can explore complex complementary as well as contradictory perspectives, and there is considerable scope for using this method in a range of long term conditions.

Based on our experiences of conducting multiperspective studies and drawing on the wider literature, we summarise when researchers might find multiperspective interviews a useful approach, discuss how to use this approach, consider the data that are generated, and highlight potential pitfalls and how to avoid these.¹⁻⁵ This paper builds on our previous article discussing the need for longitudinal qualitative approaches.⁶ Combining longitudinal and multidimensional interviews can prove particularly valuable.

When are multiperspective interviews appropriate?

Multiperspective interviews are potentially most useful when seeking to

- Understand relationships and dynamics among patients, their families, and professional carers
- Explore similarities and differences in the perceptions of patients and their family and professional carers
- Understand the individual needs of patients, carers, and professionals
- Integrate suggestions for improving services from patients, carers, and professionals.

We have used the approach mainly in the context of pallia-

tive care, where family and professional carers have an important role (table).^{1,5} Other researchers have shown the value of a multiperspective approach in diverse clinical areas including the pattern of symptoms in childhood cancer; the couple's experience of breast cancer recurrence and prostate cancer; the complex clinician-patient interactions around requests for physician-assisted suicide; and development of a model of care giving skills for relatives of people with cancer.⁷⁻¹³

Dyad combinations typically include husband-wife, mother-child, and patient-carer. Triad combinations, as in a study exploring children's, parents', and professionals' views about tissue donation for research, have been used far less often.¹⁴ In a study of patient-family dyads about information disclosure, the researchers concluded that interview triads would have given broader and deeper information.¹⁵ More recently, another study used interviews with patients, carers, and professionals to explore views about when prognostic discussions should be instigated.¹⁶

How do you conduct multiperspective interview studies?

Recruitment

Our experiences have highlighted the value of a stepwise approach starting with the patient, then recruiting an informal carer, and finally health or social care professionals. Before patients give their consent, they understand that they will be invited to nominate the family members and professional carers who are most important or central to their care. The aim is to recruit those informants most likely to have relevant information for the study. Consent is obtained from each individual in turn. The aim is to complete a set of interviews over a few days or weeks, ensuring that all participants have the opportunity to reflect on whether they wish to participate and are clearly informed that they are free to withdraw at any time without adversely affecting their or their family's care and support. We found that patients were happy and able to recommend a range of key informal carers and professionals for interview. When approached in this way, the majority of carers were willing to participate.

Data generation

We usually begin by interviewing the patient alone and then the family carer in order to generate separate accounts. However, in about half the cases in our palliative care studies the patient and family carer preferred to be interviewed together. Although this can constrain the discussions, at other times

SUMMARY POINTS

Case linked interviews with patients and their carers can generate a richer understanding of needs and experiences. Such studies can provide practical recommendations about how to deliver services. Serial multiperspective interviewing is particularly valuable in understanding changes over the course of an illness.

patients and carers were able to prompt each other to mention or expand on specific issues or experiences. Interviewing the carer simultaneously also has the advantage of allowing additional insights into the relationship. We typically interview professionals last and have found that telephone interviews, which can easily be recorded using a telephone adaptor, are the most efficient and acceptable method.

Analysis

Analysis proceeds concurrently with data generation, allowing emerging themes and concepts to be reflected on with subsequent participants. Interview transcripts and field notes from each set of patient, family, and professional carer can, however, be analysed as separate case studies and then as groups of case studies. Even a small sample will generate a variety of analytical opportunities, so qualitative software such as NVivo (www.qsrinternational.com) can be useful in organising these data.

If a longitudinal, serial dyad or triad approach is used, analysis may also be undertaken across all first interviews, then across all second and subsequent sets of interviews, or by synthesising data relating to specific key points or transitions, such as interviews with patients approaching the last days of life. By coding within as well as between cases, changes over time linked to particular patients and their associated carers and professionals can be retained and analysed in considerable depth. The context of individual patient journeys is preserved while undertaking the broader thematic analysis.¹¹ Creation of a matrix linking cases to the coding frame can help writing and interpretation, maximising the strengths of multiperspective data.

What type of findings might you expect?

Understanding of relationships and dynamics

Multiperspective interviews can enhance understanding of

interactions such as patient-carer-doctor relationships or provide rich insights into the multifaceted roles of patients within their families and communities and the way in which these serve to maintain their identity. In one case, we conducted interviews with the patient, his wife, a specialist nurse, the church minister, his general practitioner, and an overnight nurse to develop a complex account of the experience of dying at home from lung cancer.¹⁶

Comparison of perceptions of patients, their family, and carers

Interviews with patient, family, and professional sometimes show concordance in their perceptions. For example, we found that an elderly man with progressive and unstable heart failure described feelings of lack of control and helplessness that were confirmed by his wife, who added that she felt like she was in prison with him. The general practitioner was experiencing similar disempowerment because he felt that he could do very little for such people.² In our study of the end of life care needs of South Asian patients in Scotland a participant recounted how he had suffered from discrimination and generally poor care. A linked professional confirmed that this patient's dietary needs had been unmet and his treatment been discriminatory.³

However, multiperspective data can also show differing concerns among participants. In our allergy studies, adolescents and parents gave contrasting views of the readiness of adolescents to accept responsibility for managing their condition, with parents far more anxious than adolescents about the dangers of the adolescents' ability to manage risk.⁵ In a study of mothers with early breast cancer and their children, although the mothers assumed the children were unconcerned by the diagnosis, the children described themselves as being overwhelmed.¹⁷ We found some health professionals diagnosing clinical depression at the end of

Details of multiperspective interview studies

Aims of study	Patients	Informal carers	Professional carers
To compare the illness trajectories, needs, and service use of patients with cancer and those with advanced non-malignant disease ¹	20 patients with inoperable lung cancer and 20 with advanced heart failure	Spouses, daughters, cousins, warden of sheltered accommodation	General practitioners, district nurses, community palliative care nurse, cardiologist, hospital chaplain
To inform future service developments for people with advanced heart failure ²	30 patients with advanced heart failure	Spouses, daughters	General practitioners, heart failure nurses, geriatricians, day care staff, community nurses, hospice staff, voluntary workers
To understand the experience of being diagnosed and living with a brain tumour (2005-9)	26 patients with suspected malignant glioma	Spouses, parents, daughters, sisters	General practitioners, clinical oncologists, neurosurgeons, hospital nurses, palliative care nurses, district nurses, allied health professionals, social worker, hospital chaplains
To identify the needs and service use of patients with chronic obstructive pulmonary disease, and to map a framework for an intervention study (2006-9)	20 patients with severe disease	Spouses, daughters	General practitioners, respiratory physicians, community based and hospital based respiratory nurses, nurse from day hospice
To understand end of life care needs of South Asian patients in Scotland and to understand barriers and facilitators to accessing services ³	25 South Asian patients	Spouses, children	General practitioners, specialist nurses, social worker, oncologist, occupational therapist, hospital manager
To describe the spiritual needs of patients approaching death and to explain how and by whom such needs could best be met ⁴	20 patients with advanced malignant and non-malignant disease	Spouses, children, sisters	General practitioners, hospice staff
To explore the psychosocial impact of living with anaphylaxis on adolescents and their parents; their management of the condition; and perceptions of health care provision ⁵	7 adolescents with anaphylaxis	Parents	None
To explore perceptions about anaphylaxis and its management and to formulate interventions and evaluate their acceptability to adolescents, parents, and professionals (2008-9)	26 adolescents with anaphylaxis	Parents	Allergy specialists, general practitioners, specialist nurses, school nurses, psychologists, resuscitation officers, dietitians, food and drug industry representatives, voluntary sector staff

life, when the patient considered the problems to be more existential or spiritual.⁴

Understanding of individual needs of participants

Interviews with multiple people can show different facets of the needs and coping strategies of participants in their role as patient, carer, or professional. Several general practitioners, as well as describing their need for better access to community nursing and social services to support dying patients at home, acknowledged that personal stresses and a lack of adequate training in communication were important barriers to effective care.¹

Suggestions for improving services

Linked interviews not only show the complexity of individual situations and help researchers understand deficiencies in care from different perspectives, they may also contribute to formulating relevant and workable recommendations for improving services. We organised focus groups of key professionals, patients, and carers to discuss our multiperspective interview data and used the discussion to direct formulation of a framework for planning care for people with advanced heart failure.^{1,10} Interviews with bereaved carers, for example, provided in-depth accounts of their experiences that could be integrated and compared with those of the professional carers. We have also developed service recommendations by feeding back interview findings to separate groups of professional, patient, and family participants and asking them to comment on potential interventions.

Potential pitfalls and how to avoid them

Recruitment issues

Recruiting carers into a study at around the same time as the patient might seem to add complexity. Although some patients may be less willing to participate if their family carer is also to be interviewed, it can aid recruitment of vulnerable and potentially hard to access patients because the carer moves from being a protective gatekeeper to a participant.¹⁸ Inclusion of patients who may not have an obvious family carer or friend is important, and careful exploration may identify another supportive relationship—for example, a lung cancer patient identified a sheltered housing warden.¹ We have occasionally had difficulty in recruiting busy professionals identified by patients as a key informant, and competing pressures, such as work or caring for a young family can hinder participation by family carers. Flexibility about the place and time of the interview makes refusal unusual.

Patients and carers opting to be interviewed together

Interviewing participants together is appropriate if this has been requested by participants. This can, however, have costs as well as benefits. Hearing the individual voices of the patient and carer adequately and managing information that may be sensitive or personal in the context of a joint interview can be challenging. As most interviews take place in the patient's home, a carer wishing to add information sometimes takes the opportunity for a word alone when showing the interviewer out or, for example, by inviting the researcher to look at the garden. Patients might suggest the carer make a cup of tea, which then allows them to share information they did not want the carer to hear.

When interviews are separate some carers use the patient interview as an opportunity to go out or carry out short social activities. In our brain tumour study we found that some participants chose separate interviews when they had specific issues to discuss or were not coping or communicating well with their carers.

Joint interviews are particularly valuable when patients have cognitive impairment or communication difficulties.¹⁹ Steinhäuser has sought to overcome the difficulties of joint interviewing by providing two researchers to interview the patient and carer independently, but care must be taken not to impose separate, time consuming interviews on participants.²⁰

Ethical issues

The ethical pitfalls of multiperspective research should be considered at all stages of the study. When interviewing a family or professional carer after the patient, it is often helpful to build on information from the patient interview. However, care must be taken to preserve confidentiality, particularly as carers may be curious or concerned about what has been said. Ethical issues around acting on the basis of research findings may be more acute when areas of concern—for example, about quality of care or relationships—involve or are corroborated by different interviewees. This method places emotional demands on researchers, especially if generating accounts over time, so support and debriefing from senior staff must be available.

Lack of clarity about aims and analytical strategy

Clear aims and analytical methods need to be set out and agreed at the outset because the quantity of data generated can otherwise rapidly prove overwhelming. When conducting a mixture of paired and individual interviews, both separate and joint interviews should be analysed transparently in the context in which they were generated.²¹

Conclusions

To develop personalised whole person care, we need to use patient centred research methods that can capture the multidimensional nature of the illness experience and place this understanding within a familial and health service context. Concerns about the time consuming nature of the data generation and the fact that fewer participants can be sampled have limited the use of this research method. Many of the potential barriers can be overcome with appropriate planning and groundwork. Generating data from different sources can make a major contribution to identifying people's needs and preferences.²² Such studies elicit users' views about care in the context of their experiences and integrate these with those of professionals to provide practical recommendations about how services might be delivered more effectively.

We thank the Chief Scientist's Office of the Scottish Government, the Department of Health, London, Macmillan Cancer Support, the Economic and Social Research Council, and E. Wiseman for funding the studies, and Hilary Pinnock and Michael Gallagher for permitting their studies to be highlighted.

Contributors: SAM, MK, and AS conceived the paper. All the authors wrote it and have approved the final draft. MK is the guarantor.

Competing interests: None declared.

Provenance and peer review: Not commissioned; externally peer reviewed.

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Research methods and reporting

Research methods and reporting is for "how to" articles—those that discuss the nuts and bolts of doing and writing up research, are actionable and readable, and will warrant appraisal by the *BMJ*'s research team and statisticians. These articles should be aimed at a general medical audience that includes doctors of all disciplines and other health professionals working in and outside the UK. You should not assume that readers will know about organisations or practices that are specific to a single discipline.

We welcome articles on all kinds of medical and health services research methods that will be relevant and useful to *BMJ* readers, whether that research is quantitative or qualitative, clinical or not. This includes articles that propose and explain practical and theoretical developments in research methodology and for those on improving the clarity and transparency of reports about research studies, protocols, and results.

This section is for the "how?" of research, while the "what, why, when, and who cares?" will usually belong elsewhere. Studies evaluating ways to conduct and report research should go to the *BMJ*'s Research section; articles debating research concepts, frameworks, and translation into practice and policy should go to Analysis, Editorials, or Features; and those expressing personal opinions should go to Personal View.

Articles for Research methods and reporting should include:

- Up to 2000 words set out under informative subheadings. For some submissions, this might be published in full on bmj.com with a shorter version in the print *BMJ*
- A separate introduction ("standfirst") of 100-150 words

spelling out what the article is about and emphasising its importance

- Explicit evidence to support key statements and a brief explanation of the strength of the evidence (published trials, systematic reviews, observational studies, expert opinion, etc)
- No more than 20 references, in Vancouver style, presenting the evidence on which the key statements in the paper are made
- Up to three tables, boxes, or illustrations (clinical photographs, imaging, line drawings, figures—we welcome colour) to enhance the text and add to or substantiate key points made in the body of the article
- A summary box with up to four short single sentences, in the form of bullet points, highlighting the article's main points
- A box of linked information such as websites for those who want to pursue the subject in more depth (this is optional)
- Web extras: we may be able to publish on bmj.com some additional boxes, figures, references (in a separate reference list numbered w1, w2, w3, etc, and marked as such in the main text of the article)
- Suggestions for linked podcasts or video clips, as appropriate
- A statement of sources and selection criteria. As well as the standard statements of funding, competing interests, and contributorship, please provide at the end of the paper a 100-150 word paragraph (excluded from the word count) explaining the paper's provenance. This should include the relevant experience or expertise of the author(s) and the sources of information used to prepare the paper. It should also give details of each author's role in producing the article and name one as guarantor.

Appendix 3: Confirmation of Ethics Approval

Lothian NHS Board

Lothian Research Ethics Committee
Deaconess House
148 Pleasance
Edinburgh
EH8 9RS
Telephone 0131 536 9000
Fax 0131 536 9346
www.nhslothian.scot.nhs.uk



Ms Anna Lloyd
PhD Student
Edinburgh University
20 West Richmond Street
Edinburgh
EH8 9DX

Date 16 March 2009
Our Ref: 09/S1101/6
Enquiries Emily Pendleton
Extension 89028
Direct Line 0131 536 9028
emily.pendleton@nhslothian.scot.nhs.uk

Dear Ms Lloyd

Full title of study: Understanding the changing care needs of the frail elderly using a multiperspective longitudinal qualitative research method.

REC reference number: 09/S1101/6

Thank you for your letter of 04 March 2009, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair and the LREC Scientific Adviser.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.



Headquarters
Deaconess House 148 Pleasance Edinburgh EH8 9RS

Chair Dr Charles J Winstanley
Chief Executive Professor James J Barbour O.B.E.
Lothian NHS Board is the common name of Lothian Health Board

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review –guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

09/S1101/6 ~ Please quote this number on all correspondence
--

With the Committee's best wishes for the success of this project

Yours sincerely

A handwritten signature in black ink, appearing to read 'Mr Grier'.

Mr Nicholas Grier
Chair

Enclosures: "After ethical review – guidance for researchers"

Copy to: NHS Lothian R&D Office

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Response to Request for Further Information		04 March 2009
Participant Consent Form: Older Person	v3	04 March 2009
Participant Information Sheet: Carer	v2	04 March 2009
Participant Information Sheet: Older Person	v2	04 March 2009
Consent to contact Carer/Professionals	V.1	18 December 2008
Thank You Letter Older Person/Carer	V.1	18 December 2008
Interview Guide Professional	V.1.	18 December 2008
Interview Guide Carer	V.1	18 December 2008
Participant Consent Form: Professional	V.1	18 December 2008
Participant Consent Form: Carer	V.2	18 December 2008
Letter of invitation to participant: Professional	V.1	18 December 2008
Questionnaire: Open Ended	V.1	18 December 2008
Questionnaire		
Interview Schedules/Topic Guides: Older Person	V.1	18 December 2008
Letter from Sponsor		
Summary/Synopsis		11 December 2008
Protocol	V.2	18 December 2008
Investigator CV - Prof. Scott A Murray		
Application	V.2	
Student C.V. - Anna	V1	21 December 2008
GP/Consultant Information Sheets	V.1	21 December 2008
Letter of invitation to participant: Carer	V.1	21 December 2008
Summary/Synopsis	V.1	18 December 2008

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

Lothian NHS Board

Lothian Research Ethics Committees
Deaconess House
148 Pleasance
Edinburgh
EH8 9RS
Telephone 0131 536 9000
Fax 0131 536 9346
www.nhslothian.scot.nhs.uk



18 February 2010

Ms Anna Lloyd
PhD Student
Edinburgh University
PhD Student
20 West Richmond Street
Edinburgh
EH8 9DX

Date 18 February 2010
Our Ref. 09/S1101/6
Enquiries Emily Pendleton
Extension 89027
Direct Line 0131 536 9027
Emily.pendleton@nhslothian.scot.nhs.uk

Dear Ms Lloyd

Study title: Understanding the changing care needs of the frail elderly using a multiperspective longitudinal qualitative research method.
REC reference: 09/S1101/6
Amendment number:
Amendment date: 14 January 2010

The above amendment was reviewed at the meeting of the Sub-Committee held on 17 February 2010 by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Letter of invitation to participant	1	14 January 2010
Protocol	3	14 January 2010
Notice of Substantial Amendment (non-CTIMPs)		14 January 2010

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.



Headquarters
Deaconess House 148 Pleasance Edinburgh EH8 9RS

Chair Dr Charles J Winstanley
Chief Executive Professor James J Barbour O.B.E.
Lothian NHS Board is the common name of Lothian Health Board

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

09/S1101/6:	Please quote this number on all correspondence
-------------	--

Yours sincerely

Emily Pendleton
Committee Co-ordinator

E-mail: emily.pendleton@nhslothian.scot.nhs.uk

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Mrs Elspeth Currie*

Appendix 4: Participant Information Sheet



Understanding the experiences and needs of older people.

DIVISION of COMMUNITY HEALTH
SCIENCES
GENERAL PRACTICE SECTION
The University of Edinburgh
20 West Richmond Street
Edinburgh. EH8 9DX.
Tel: 0131 650 3209
E-mail: A.E.Lloyd@sms.ed.ac.uk

This is an invitation to take part in a research study. Before you decide if you want to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

We are looking to find out more about the experiences and needs of older people who have begun to need a little more help with their day to day lives so that we can better help people in the future. We would like to hear about your experiences of life at this stage and about the services and care that you receive. We also want to know about how your needs and experiences change over a period of 12 to 18 months. We would also like to hear about the experiences of your carer at home and the health professional that is most involved in your care. Therefore, if you agree we will also approach them for interview. We would like to hear about all your experiences, good or bad, which will help to improve future health and social care. At, times, talking about your experiences and needs can touch upon sensitive issues, however, you do not need to discuss anything that you would rather not and can stop an interview at any time with no need to offer an explanation.

Why have I been chosen?

You have been chosen as you have been attending a day hospital or outpatients unit and you may be beginning to need a little more help with your day to day activities.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you think you may wish to take part, you will be given this information sheet to keep by the researcher, Mrs Anna Lloyd. She can answer any questions that you may have and will contact you by telephone in approximately 2 days time to hear if you have decided to take part.

Can I change my mind about taking part?

Yes. If you decide to take part you may change your mind at any time and without giving a reason. A decision to withdraw, or a decision not to take part, will not affect the standard of care you receive either now or in the future.

What will happen to me if I take part?

If you are happy to take part in the study when the researcher, Mrs Lloyd telephones, she will arrange a convenient time and place to you for the first interview.

The first interview

The first interview can be in your own home or at the day hospital or outpatients clinic and you will be asked to sign a consent form. The interview will be about how you feel, about any care or treatment you may be receiving and any other issues you wish to discuss. Interviews usually last for about 40 – 60 minutes, but you can break off at any time for any reason. Interviews may also be stopped by Mrs Lloyd if it appears that it is becoming tiring or difficult for you and in which case she will ask your permission to contact someone close to you or the day hospital or outpatient staff to offer support. If you agree, the interviews will be recorded so that we can be sure that we remember and understand what you say correctly. The recording will not be heard by anyone other than the researchers and will be kept securely. You may listen to the recording, or read the transcript if you wish to do so.

Two further interviews over 12 to 18 months

The researcher will contact you by telephone every 2 months to hear how you are doing and, if you are still willing to take part, will arrange two further interviews at over a period of up to 18 months. On each occasion we will ask about how are keeping, about any care you are receiving and any further issues you wish to discuss.

After the third interview has taken place, you will be given a very short questionnaire asking about your views on taking part in the study.

Relatives, carers and professionals

If there is someone who helps and supports you at home (a relative or a good friend), or a carer who helps you, or a doctor or nurse who looks after you, we will ask you if we can approach them and invite them to be interviewed as well. These interviews will also be recorded. We will ask them similar questions so that we can understand their point of view as well. We will not speak to anyone without your consent.

Is there anything else you want to know about me?

We would also like your permission for the researcher to review your medical records. This helps us to understand any treatments you have had or recent difficulties which may be relevant to your care.

What are the possible benefits of taking part?

This study does not set out to offer direct personal benefits to you, but by helping us to understand your experiences; we hope that others at a similar stage in life who may be experiencing similar difficulties or problems will get the best possible care in the future.

Are there any risks?

No. There are no foreseeable risks. Your care will not be affected: we are only asking you to tell us about how you are keeping and the care you receive. There are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action.

Will my taking part in the study be kept confidential?

Yes. Your name will not be known to anyone other than the researcher and no information will be given to anyone outside the research group. Your consultant and GP will be informed that you are taking part in the study: this is to ensure that they are happy that you are well enough to take part. If at interview we discover something which we feel either the hospital consultant or your GP should know about, we would discuss it with you and ask your permission to let them know. We will not pass on any information without your permission. All the recordings will be destroyed in due course.

What will happen to the results of the research study?

The results of the study will be written as a report in the first instance and subsequently published in medical and other academic journals in order to help others in the field understand your needs and ultimately improve future patient care. You will not be identifiable in any of these reports and everyone who takes part in the study will be offered a summary of the results.

Who is organising and funding the study?

Anna Lloyd, a PhD student is leading the research project with the support of Professor Scott Murray, Dr Marilyn Kendall and Professor John Starr at the University of Edinburgh. The study is funded by the Economic and Social Research Council and supported by the University of Edinburgh. The study has been approved by the Local Research Ethics Committee in Edinburgh.

What if you have some questions about the study?

If you would like to ask any questions about participating in the study you can contact Mrs Anna Lloyd 0131 650 3209 or email at A.E.Lloyd@sms.ed.ac.uk. You may have to leave a message but we will return you call as soon as possible.

(Please note that we can only answer questions about the study – you should discuss any other health concerns with your general practitioner in the normal way)

Any complaints or concerns about this study should be directed to Dr Donald Thomson: Telephone: 0131 650 9496. E-mail: Donald.Thomson@ed.ac.uk. The normal National Health Service complaints mechanisms are also available to you.

What happens now?

- If you agree, your day hospital/out patient doctor or specialist nurse will give your name and telephone number to Anna Lloyd, the study researcher.
- In a few days time Anna will phone to ask if you are interested in taking part in the study. She can answer any questions you may have. If you are not sure, she can answer any questions you may have, and can phone back another day. If you have decided you do not want to take part, you will not be asked why or have any attempts made to try to persuade you.
- If, at any point you wish to speak with an independent person from the University of Edinburgh regarding the study you may contact Dr Donald Thomson at the McKenzie Medical Centre or telephone 0131 650 9496.

Thank you for taking the time to read this information sheet and please don't hesitate to contact us if you have any questions

Appendix 5: Permission to contact carer/professional



Understanding the experiences and needs of older people.

CONSENT TO CONTACT CARERS/PROFESSIONALS

Name of Researcher: Mrs Anna Lloyd

I am happy for Mrs Anna Lloyd to contact my carers, whose details are listed here, and invite them to be interviewed about how they help me.

Name _____

Signature _____

Date _____

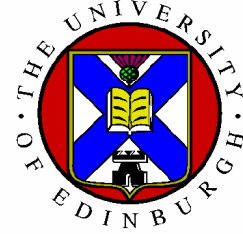
Contact details: Carer at home

Name	
Address	
Telephone	
E-mail	
Notes:	

Contact details: Health/Social care professional

Name	
Address	
Telephone	
E-mail	
Notes:	

Appendix 6: Carer Information Sheet



Understanding the experiences and needs of older people.

DIVISION of COMMUNITY HEALTH
SCIENCES
GENERAL PRACTICE SECTION
The University of Edinburgh
20 West Richmond Street
Edinburgh. EH8 9DX.
Tel: 0131 650 3209
E-mail: A.E.Lloyd@sms.ed.ac.uk

This is an invitation to take part in a research study. Before you decide if you want to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

We are looking to find out more about the experiences and needs of older people who have begun to need a little more help with their day to day lives so that we can better help people in the future. We would like to hear your perspective regarding the experiences of someone at this stage and about the services and care that they receive. We also want to know about how their needs and experiences change over a period of 12 to 18 months. We would like to hear about all your views on the experiences of the older person, good or bad, which will help to improve future health and social care. At, times, talking about such experiences and needs can touch upon sensitive issues, however, you do not need to discuss anything that you would rather not and can stop an interview at any time with no need to offer an explanation.

Why have I been chosen?

You have been chosen as you have been nominated by an older person attending a day hospital or outpatients unit who may be beginning to need a little more help with day to day activities as being involved with them.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you think you may wish to take part, you will be given this information sheet to keep by the researcher, Mrs Anna Lloyd. She can answer any questions that you may have and will contact you by telephone in approximately 2 days time to hear if you have decided to take part.

Can I change my mind about taking part?

Yes. If you decide to take part you may change your mind at any time and without giving a reason. A decision to withdraw, or a decision not to take part, will not affect the standard of care received by the older person either now or in the future.

What will happen to me if I take part?

If you are happy to take part in the study when the researcher, Mrs Lloyd, telephones she will arrange a convenient time and place to you for the first interview.

The first interview

The first interview can be in your own home or at the day hospital or outpatients clinic and you will be asked to sign a consent form. The interview will be about any care or treatment the older person may be receiving and any other issues you wish to discuss. Interviews usually last for about 40 – 60 minutes, but you can break off at any time for any reason. Interviews may also be stopped by Mrs Lloyd if it appears that it is becoming tiring or difficult for you. If you agree, the interviews will be recorded so that we can be sure that we remember and understand what you say correctly. The recording will not be heard by anyone other than the researchers and will be kept securely. You may listen to the recording, or read the transcript if you wish to do so.

Two further interviews over 12 to 18 months

The researcher will contact the older person by telephone every 2 months to hear they are doing and, if they are still willing to take part, will arrange two further interviews with you and them over a period of up to 18 months. On each occasion we will ask about how the older person is keeping, about any care they are receiving and any further issues you wish to discuss. After the third interview has taken place, you will be given a very short questionnaire asking about your views on taking part in the study.

What are the possible benefits of taking part?

This study does not set out to offer direct personal benefits to you or the older person, but by helping us to understand their experiences; we hope that others at a similar stage in life who may be experiencing similar difficulties or problems will get the best possible care in the future.

Are there any risks?

No. There are no foreseeable risks. The older person's care will not be affected: we are only asking you to tell us about how they are keeping and the care they receive. There are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action.

Will my taking part in the study be kept confidential?

Yes. Your name will not be known to anyone other than the researcher and no information will be given to anyone outside the research group. If at interview we discover something which we feel either the hospital consultant or your GP should know about, we would discuss it with you and ask your permission to let them know. We will not pass on any information without your permission. All the recordings will be destroyed in due course.

What will happen to the results of the research study?

The results of the study will be written as a report in the first instance and subsequently published in medical and other academic journals in order to help others in the field understand your needs and ultimately improve future patient care. You will not be identifiable in any of these reports and everyone who takes part in the study will be offered a summary of the results.

Who is organising and funding the study?

Anna Lloyd, a PhD student is leading the research project with the support of Professor Scott Murray, Dr Marilyn Kendall and Professor John Starr at the University of Edinburgh. The study is funded by the Economic and Social Research Council and supported by the University of Edinburgh. The study has been approved by the Local Research Ethics Committee in Edinburgh.

What if you have some questions about the study?

If you would like to ask any questions about participating in the study you can contact Mrs Anna Lloyd 0131 650 3209 or email at A.E.Lloyd@sms.ed.ac.uk. You may have to leave a message but we will return you call as soon as possible.

(Please note that we can only answer questions about the study – you should discuss any other health concerns with your general practitioner in the normal way)

Any complaints or concerns about this study should be directed to Dr Donald Thomson: Telephone: 0131 650 9496. E-mail: Donald.Thomson@ed.ac.uk. The normal National Health Service complaints mechanisms are also available to you.

What happens now?

- In a few days time Anna will phone to ask if you are interested in taking part in the study. She can answer any questions you may have. If you are not sure, she can answer any questions you may have, and can phone back another day. If you have decided you do not want to take part, you will not be asked why or have any attempts made to try to persuade you.
- If, at any point you wish to speak with an independent person from the University of Edinburgh regarding the study you may contact Dr Donald Thomson at the McKenzie Medical Centre or telephone 0131 650 9496.

Any complaints or concerns about this study should be directed to Dr Donald Thomson: Telephone: 0131 650 9496. E-mail: Donald.Thomson@ed.ac.uk. The normal National Health Service complaints mechanisms are also available to you.

Thank you for taking the time to read this information sheet and please don't hesitate to contact us if you have any questions

Appendix 7: Participant Consent form

Understanding the experiences and needs of older people



CONSENT FORM: Older person

Name of Researcher: Mrs Anna Lloyd

Please initial

I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions	
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my medical care or legal rights being affected	
I agree that if I have to withdraw from the study for any reason my data up to that point may be used in the results of the study, but only with my consent.	
I understand that the study will involve me participating in up to 3 interviews over 12 to 18 months and that these interviews will be audio-recorded and kept securely, at the University of Edinburgh, for 5 years.	
I agree to my GP being informed of my participation in the study	
I give the researcher, Mrs Lloyd, permission to access my medical notes	
I agree to take part in the above study	

Name of participant

Date

Signature

Researcher

Date

Signature

Appendix 8: Carer Consent Form

Understanding the experiences and needs of older people



CONSENT FORM: Carer

Name of Researcher: Mrs Anna Lloyd

Name of participant:

Please initial

I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions	
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without affecting the medical care or legal rights of the person I care for	
I agree that if I have to withdraw from the study for any reason my data up to that point may be used in the results of the study	
I understand that the study will involve me participating in up to 3 interviews over 12 to 18 months and that these interviews will be audio-recorded and kept securely, at the University of Edinburgh, for 5 years	
I agree to take part in the above study	

Name of participant

Date

Signature

Researcher

Date

Signature

Thank you for helping us with this study.

Appendix 9: Professional Invitation Letter



Name
Address

Date

Dear *name*,

Understanding the experiences and needs of older people

I am writing to ask for your help with a research study which aims to find out what it is like to become older and begin to need a little more help with day to day activities.

We are also interested in the views of those that look after someone at this stage, so that we can better help others in similar situations. *Patient's name* is participating in the study and has given us your name as someone who helps *him/her* and has agreed that we may talk to you about *his/her* experiences and care needs.

The enclosed information leaflet tells you about the study. We are interested to hear of any experiences which could be improved and also any suggestions you might have about improving the care in the future.

Please read the leaflet carefully, and discuss it with friends or family if you wish. I will contact you in a few days time to answer any questions about the study.

Thank you for considering whether to participate in the study.

Yours sincerely

Mrs Anna Lloyd

Appendix 10: Professional Consent Form



Understanding the experiences and needs of older people

CONSENT FORM: Professional Carer

Name of Researcher: Mrs Anna Lloyd

Please initial box

I confirm that I have read and understand the information sheet (version and date) for the above study and have had the opportunity to ask questions	
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. My decision will not affect my employment or promotion prospects, or the medical care or legal rights of the person I care for.	
I understand that the study will involve me in one, or up to four interviews over 12 months, and that these interviews will be audio-recorded.	
I agree to take part in the above study	

Name of participant

Date

Signature

Researcher

Date

Signature

Appendix 11: Interview Guide

Interview Guide

Interview Strategy

The interview schedule is designed as an outline only, as participants will be encouraged to discuss their experiences and needs from their own perspective. The emphasis will remain on what they regard as important rather than attempting to follow an established interview framework. The guide will be utilised in a flexible manner that is responsive to the participant and the researcher will ask a series of open ended questions and respond to patient cues to move the interview forward.

1. Setting the Scene

a. Events to date

- i. When did you start to need a little more help with day to day living?
- ii. How long ago was that?
- iii. How did you cope with that?

b. Current Situation

- i. How are you feeling at the moment?
- ii. Are there any current problems?
- iii. What are the contributing factors to these problems?
- iv. How could these problems be overcome?

c. Services

- i. What services do you use?
- ii. When did these start?
- iii. How were you made aware of these services?
- iv. What are your experiences of these services?
- v. Are there services that you are aware of that have not been offered or discussed with you? How did you hear about these services?
- vi. In what way do you think they would be useful for you?

2. Needs

a. Physical Needs

- i. What are your main physical problems?
- ii. How do these affect your everyday life?
- iii. How are these problems dealt with in the community?
- iv. Do you feel they are dealt with appropriately?

b. Psychological Needs

- i. How are you feeling in yourself at the moment?
- ii. How does this compare with the past?
- iii. Do you ever feel depressed or low?

- iv. What are your current worries?
- c. *Spiritual Needs*
 - i. How do you cope with your stage in life?
 - ii. Does anything/anyone help you cope?
 - iii. What do you particularly value in life?
 - iv. Do you ever think about the future?
 - v. Would you describe yourself as a spiritual person?
- d. *Social Needs*
 - i. Do you still manage to get out and about? Do you see your friends?

3. Communication

- a. *Communication with professionals*
 - i. How do you find talking to your doctor/nurse?
 - ii. Do you generally understand what they say to you?
 - iii. Do you like to ask questions?
 - iv. Have you been given the opportunity to ask question?
 - v. Is there anything specific that the doctor/nurse has done to help you understand your situation?
 - vi. Do they explain your medications and what they are for?
 - vii. Is there any one professional that you feel understands your situation particularly well?
 - viii. Why do you think this is?
- b. *Communication with relatives*
 - i. Do you often talk to your relatives about how you are?
 - ii. How do you find this?
 - iii. How do you think they find this?
 - iv. Do you think it is important to talk to them about it?
 - v. Is there anyone in particular that you talk to?
 - vi. Do you worry about talking to your relatives?
- c. *Involvement in decision making*
 - i. How do you feel about making choices about help or care?
 - ii. Do you feel that you can have your say?
 - iii. Do you feel that your wishes are respected?

4. Suggestions for the future

- a. *Future Care*
 - i. How do think we could improve care for others like you in similar circumstances?
 - ii. Do you think there are any major problems with the current provision of services?

Appendix 12 CSHA Clinical Frailty Scale

Box 1: The CSHA Clinical Frailty Scale

- 1 *Very fit* — robust, active, energetic, well motivated and fit; these people commonly exercise regularly and are in the most fit group for their age
- 2 *Well* — without active disease, but less fit than people in category 1
- 3 *Well, with treated comorbid disease* — disease symptoms are well controlled compared with those in category 4
- 4 *Apparently vulnerable* — although not frankly dependent, these people commonly complain of being “slowed up” or have disease symptoms
- 5 *Mildly frail* — with limited dependence on others for instrumental activities of daily living
- 6 *Moderately frail* — help is needed with both instrumental and non-instrumental activities of daily living
- 7 *Severely frail* — completely dependent on others for the activities of daily living, or terminally ill

Note: CSHA = Canadian Study of Health and Aging.